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Voices from the Margins

Systematic Review: Fathers' Experiences of their Partners' Postpartum Depression:

A Systematic Review and Thematic Synthesis

Empirical Study: 'Treated as a person, not a case': Exploring meaning-making in
an Open Dialogue informed mental health service

Thesis presented by

Niamh Doyle

for the degree of

Doctor of Clinical Psychology



University College Cork

School of Applied Psychology

May 2019

Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism.

Signed,

Niamh Doyle

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1 Chapter One: Systematic Review

Title: Fathers' experiences of their partners' Postpartum Depression: A systematic review and thematic synthesis

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Fathers' Experiences of their Partners' Postpartum Depression: A Systematic Review and Thematic Synthesis

Niamh Doyle^a, M. Hammond^b, M. Murphy^a and M. Dempsey^a

Correspondence to: Niamh Doyle, School of Applied Psychology, University

College Cork, Cork, Ireland; 116222795@umail.ucc.ie

^a *School of Applied Psychology, University College Cork, Cork, Ireland*

^b *Department of Psychology, Beaumont Hospital, Dublin, Ireland*

Fathers' experiences of their partners' Postpartum Depression: A systematic review and thematic synthesis

Background: A father's understanding, management and support of his partner through maternal postpartum depression (PPD) has implications for the mother's recovery, the couple relationship and infant development. *Aim:* To systematically review qualitative research investigating fathers' experiences of their partners' PPD. *Method:* The following databases were searched from inception to October 2018: Academic Search Complete, MEDLINE, PsycINFO, PsycARTICLES, Psychology & Behavioral Sciences Collection, CINAHL and Maternity & Infant Care. Inclusion criteria were qualitative or mixed methodology, English language papers, and fathers as primary informants, whose partners had a current or previous diagnosis of PPD. Eight studies were included for thematic synthesis, with a combined sample size of 67. Overarching themes were: Understanding PPD; Relationships; Supporting a Partner with PPD; Burden of PPD; and Supporting Fathers. *Conclusion:* There has been limited research on this topic over the past two decades. Key limitations of studies include the prevalence of snowball sampling methods and lack of information about fathers' previous mental health history. Findings point to fathers' limited understanding of maternal PPD, a desire to be included in interventions, and a negative impact on fathers' well-being and parenting capacity. There is a need for increased psychoeducation, father support, and partner-inclusive interventions.

Keywords: systematic review, fathers, postpartum depression, mental health, qualitative research

1.1 Introduction

Postpartum Depression (PPD) is a global health concern, with a worldwide prevalence of 17.7% (Hahn-Holbrook, Cornwell-Hinrichs, & Anaya, 2018). The impact of maternal PPD on the mother and infant has been well established; it places mothers at higher risk for future depression (Llewellyn, Stowe, & Nemeroff, 1997), children at risk for social, emotional and cognitive difficulties (Junge et al., 2017; Luoma et al., 2001) and is associated with poorer satisfaction in the couple relationship (Małus, Szyluk, Galińska-Skok, & Konarzewska, 2016). Current interventions focus almost

exclusively on the mother as an individual and have only modest outcomes: between 40 and 60% achieve remission and the majority do not ever seek treatment (De Crescenzo, Perelli, Armando, & Vicari, 2014; Stuart & Koleva, 2014).

Unfortunately, fathers often have difficulty understanding their partners' PPD and can feel at a loss to know how to help (Heading, & Connor, 2006; Nicole et al., 2007). They are at increased risk for experiencing depression and parenting stress (Cameron, Sedov, & Tomfohr-Madsen, 2016; Goodman, 2008) and demonstrate less optimal interactions with their infants (Goodman, 2008). Moreover, PPD has a negative impact on the couple relationship, often resulting in conflict and relational distress (Pilkington, Milne, Cairns, Lewis, & Whelan, 2015). Fathers can be important sources of support to their partners (Montgomery, Bailey, Purdon, Snelling, & Kauppi, 2009) and when mothers perceive their partners to be supportive, they are likely to have fewer PPD symptoms and engage in higher activity levels (Almutairi et al., 2017; Saligheh, Rooney, McNamara, & Kane, 2014). Furthermore, where fathers maintain positive mental health, their partners with PPD show better quality emotional involvement with their infants (Ray, 2017).

Taken together, it is reasonable to conclude that the way in which fathers understand, cope with and support their partner throughout this illness has important implications for the mother's recovery, the couple relationship and the infant's development. Accordingly, there has been a recent surge of interest in partner-inclusive interventions for maternal PPD (Cohen & Schiller, 2017; Pilkington et al., 2015). As these interventions are developed, it is important to consider fathers' experiences of their partners' mental health and utilise their experiences to inform clinical practice and health policy.

This review aims to systematically investigate studies that have explored fathers' experiences of their partners' PPD. There is a dearth of quantitative research in this area, and to the researcher's knowledge, it has been limited to date on quantitative measures of stress and postpartum depression among fathers (e.g., Cameron, Sedov, & Tomfohr-Madsen, 2016; Goodman, 2008). For example, international reviews show that approximately 10% of fathers have symptoms of postpartum depression three to six months after delivery, which is higher where there partner also experiences PPD (Paulson & Bazemore, 2010). In a study of 38 couples, spouses of mothers with PPD were found to rate themselves, their marital relationship and their child more negatively than controls (Milgrom & McCloud, 1996). As qualitative research is best suited to exploring individual perspectives and experiences, this review will focus exclusively on qualitative studies (Al-Busaidi, 2008). Understanding their experiences may help inform preventative and treatment options for mothers, couples and fathers in the context of maternal PPD. Given the growing recognition of men's health at a policy level (Richardson, 2013), in addition to the recent interest in couple-based interventions for maternal PPD, this review is timely.

1.1.1 Research Questions

The research question for this review was: How do fathers experience their partner's PPD?

1.2 Methodology

1.2.1 Search Strategy

The following databases were searched from the inception of the database to October 2018: Academic Search Complete, MEDLINE, PsycINFO, PsycARTICLES, Psychology & Behavioral Sciences Collection, CINAHL and Maternity & Infant Care.

The search strategy included the following keywords: (belie* OR account OR impact OR needs OR understand* OR view* OR experienc* OR perspective* OR attitude* OR narrativ* OR perception) AND (((post-partum OR post-natal OR peri-natal OR postpartum OR postnatal OR perinatal) AND (depress*))) AND (man OR boyfriend* OR partner* OR father* OR husband* OR dad OR daddy OR men OR paternal* OR spous* OR male) with medical subject heading terms adapted for each database (Appendix B). The first 30 pages of Google Scholar were also searched, and reference lists of included papers were scanned to identify relevant papers.

Inclusion criteria encompassed studies using: qualitative or mixed methodology; studies written in the English language; and research investigating fathers as the primary informants, whose female partners had a current or previous diagnosis of Postpartum Depression or who self-reported themselves as having Postpartum Depression occurring within one year postpartum. Doctoral theses, dissertations and non-peer reviewed studies were also included to reduce risk of publication bias. Exclusion criteria were studies using exclusively quantitative methodology and research papers which did not have a valid or recognised method of qualitative analysis. Studies were excluded if they focused on fathers' experiences of parenting, stress or partners' physical ill-health, where Postpartum Depression may feature but was not the primary focus. Non-English language papers were also excluded as translation was outside the scope of this study. Studies investigating partners of women with pre-existing depression, other comorbid psychiatric disorders or major medical problems were excluded as it was assumed that this group would be qualitatively distinctive from those with no previous mental health difficulties. Book reviews, opinion pieces and literature reviews were also excluded.

1.2.2 Quality Assurance

The quality of remaining studies was assessed by two independent reviewers (TCP and researcher) using the Critical Appraisal Skills Programme qualitative assessment checklist (Critical Appraisal Skills Programme (CASP), 2014). Papers were categorised into categories of ‘strong’, ‘medium’, and ‘weak’, using the CASP 10-point scoring scale. Thresholds for these categories were based on previous research, with strong papers achieving 8-10, medium 5-7 and weak 1-4 (e.g. Lo, Patel & Roberts, 2015). Papers categorised as ‘weak’ were excluded from analysis.

1.2.3 Data Extraction

The primary author (Trainee Clinical Psychologist; TCP) initially screened titles and abstracts for eligibility. Articles that were clearly not related to the research question were excluded. Full-text articles of potentially eligible studies were then reviewed by the primary author and an Assistant Psychologist (AP). Where full texts were not available, authors were contacted on ResearchGate and applications were sent through the university to request access. Full texts were excluded at this stage if the articles did not meet the inclusion/exclusion and if they were characterised as ‘Weak’ in the quality review (see Figure 1). Any discrepancies in determining eligibility that could not be resolved through discussion were sent to a third reviewer for a decision.

Demographic and methodological data from each included study were extracted (see Table 1). Extracting data from qualitative research is complicated by varied reporting styles and misrepresentation of data as findings (as for example when data are used to ‘let participants speak for themselves’). The current protocol addresses this problem by following Thomas and Harden’s (2008) data extraction procedure for qualitative systematic reviews, whereby all content within the ‘Results’ or ‘Findings’ section was considered data and was coded line-by-line. This included first-order data

(e.g. quotations by participants) and second-order data (e.g. descriptions of findings, author interpretations, descriptions of themes). Each sentence had at least one code assigned.

1.2.4 Thematic Synthesis

A meta-synthesis was used to reinterpret the qualitative data into a higher level of abstraction, using thematic analytic techniques by Thomas and Harden (2008). Two reviewers (TCP and AP) grouped initial codes into over-arching themes, adding new codes where necessary to allow translation of concepts across studies.

Table 1: Demographic and Methodological Information

Reference	Country	Participants	Sample size	Data	Analysis	Quality Rating	Summary of themes
(O'Brien, 2016)	United States of America	Income: Mean montly household income \$9,430 (range \$4,300-\$17,000) Education 16 completed a bachelor's degree; one associates degree; three some college classes without completing a degree; 10 graduate education (Mean number of years of education: 16.1) Age range: 26-45 (mean 35.1) Ethnicity: Majority of participants identified as Caucasian; 16 of Western European decent; two American born Chinese decent; two ethnically Jewish PPD diagnosis: mother diagnosed with Postpartum Depression after the birth of first child Family: Nine married couples; one long-term committed relationship; Two couples expecting their second child at the time of interviews and two had more than one child	10 couples	Interviews with couples (together and separately)	Interpretative Phenomenological Analysis	Strong	Dismissal; Acknowledgement; Accommodation; Transition to parenthood; Interpersonal relationship; Functioning of the household; patterns of interaction and coping
(Allen, 2010)	United States of America	Income: No information Education: Two doctorate degrees; Two bachelors degree; three high school; one some college courses Age range: 28-39 Ethnicity: Four Caucasian; one Vietnamese; one Hispanic; one Pacific Islander; one African American PPD diagnosis: Partners diagnosed with Postpartum depression in last five years.	8	Interviews with fathers	Moustakas's transcendental phenomenological approach	Strong	Impact of PPD on the father; Impact of PPD on the family system; Barriers to receiving and seeking help; Ways of coping; Father's wants
(Letourneau, Duffett-Leger, Dennis, Stewart, &	Canada	Income: Majority reported household incomes >\$70,000 Education: Three graduates of a technical school; three college or university undergraduate degree; three graduate programme Age range: 29-44 (mean 37)	11	Telephone interviews	Thematic content analysis	Medium	Depressive symptoms of fathers; fathers' understanding of PPD; Fathers'

Tryphonopoulos, 2011)		Ethnicity: All born in Canada with English as first language PPD diagnosis: Partners reported symptoms of PPD during their last pregnancy. Family: Six fathers had one child with their partner; two fathers had lost a child within the first year of life.					coping mechanisms; support needs; barriers to accessing support
(Smith, 2013)	United States of America	Income range: \$15000->60000 (mean \$43000) Highest Education level: four college graduates, one with some college, two high school graduates Age range: 22-52 (mean 31) Ethnicity: Seven Caucasian PPD diagnosis: Partners had a previous diagnosis of PPD Family: three participants had two children; three had three children; one participant had four children	7	Interviews	Speigelberg's (1965, 1975) methodology	Strong	Vulnerability when partner's behaviour changed; rationalising causes of changes; need to make things better for the family; helplessness; coping
(Siverns, 2012)	Canada	Income: Six estimated income >\$49,999; Three <\$40000 Education: Highest Level of Education: six had some or completed community college/technical school; three had a bachelor's degree Age range: Age range 23-42 (mean 32.6) Ethnicity: Eight Caucasians; One Chinese PPD diagnosis: Not required	10	Photo-elicitation interviews	Content analysis	Strong	From two to three; Connecting with baby; Postpartum Depression and the partner relationship; Heightened involvement with baby; Available and desired supports
(Meighan, Davis, Thomas, & Droppleman, 1999)	United States of America		8	Interviews	Analysis according to the procedure specified by Pollio, Henley & Thomson (1997)	Medium	Loss of a partner and relationship; loss of control; loss of intimacy; loss of how things used to be; unsuccessful attempts to find help in the health care system

(Letourneau et al., 2012)	Canada	Age range: 23-46 (mean 37) Ethnicity: 36 Canada; 4 immigrants (United States, Denmark, United Kingdom) Family: 39 fathers married/cohabiting; 1 divorced Education: Graduates of technical school (<i>n</i> =11); college or university undergraduate programme (<i>n</i> =14); graduate programme (<i>n</i> =10) Income: Yearly household incomes >Canadian \$90,000 (<i>n</i> =20)	40	Telephone interviews	Thematic Content Analysis	Strong	Support needs and preferences for coping with partner's PPD and own depressive symptoms
(Beestin, Hugh-Jones, & Gough, 2014)	United Kindgom	Age range: 25-50 (mean 33.9). Ethnicity: 11 White-British; 1 White-Irish; 2 Black-Caribbean PPD diagnosis: Not required	14	Interviews	Interpretative Phenomenological Analysis	Medium	Physical and/or psychological absence of their partner; Fathering as a lonely and burdensome experience; fathering thwarted; father-child dyad

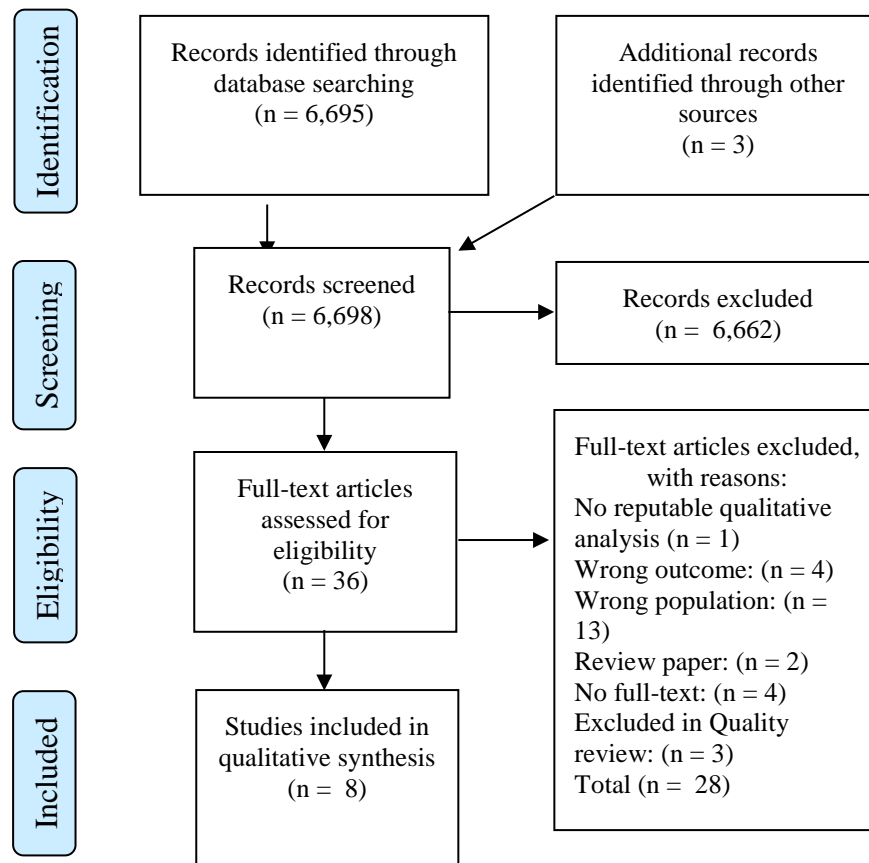


Figure 1: Data Extraction Process

1.3 Results

1.3.1 *Studies and Participants*

Database searching yielded a total of 6,695 results, of which 36 full-text articles were screened for eligibility (see Figure 1 for reasons for exclusion). 20 papers were excluded based on not meeting the inclusion/exclusion criteria. Four papers were excluded as no full-texts could be accessed. Three of the remaining studies were identified as 'Weak' in the quality review and excluded from the analysis. Eight studies were included for thematic synthesis (Table 1). Seven of these studies interviewed fathers alone and one study interviewed both fathers and mothers together and separately. Combined sample size for the eight studies was 67 (excluding women interviewed), and the studies were conducted in the United States of America ($n = 4$), Canada ($n = 3$) and the United Kingdom ($n = 1$). Participants were recruited from a range of sources, including through blog spots, community websites, health care professionals and through their partners by advertising the study in parenting groups, Postpartum Depression support groups, Labour/delivery/postpartum units, and community agencies. Many studies also used snowball sampling. All included studies collected data through interviews, two of which used telephone interview methods.

Five overarching themes were established: Understanding PPD, Relationships, Supporting a Partner with PPD, Burden of PPD and Supporting Fathers.

1.8.1 *Quality of Studies*

Regarding the quality of the studies, studies were strong on having a clear statement of the aims of research and appropriate research design and recruitment strategy. Studies that were excluded were limited by not considering the relationship between the researcher and participants, nor did they state how they addressed ethical issues.

Notably, participants in one excluded study were recruited from a service where the researcher served as a therapist. This introduced risk for perceived coercion as well as potentially impacting the preparedness of participants to speak openly about their experience. In four studies, the reported data analysis did not appear sufficiently rigorous, although this may be due to word count limits.

1.3.2 Theme One: Understanding Postpartum Depression

1.3.2.1 Lack of awareness

Many participants reported that they had not considered the possibility of PPD prior to the birth of their baby (Allen, 2010; Letourneau et al., 2011). Some expressed anger and frustration at their lack of awareness (Letourneau et al., 2011) and commented that this led to increased stress, confusion about their partner's symptoms and delayed recognition of a problem (Allen, 2010; Letourneau et al., 2011; Siverns, 2012; Smith, 2013). Many fathers questioned their role in the development of their partner's PPD, taking responsibility or blame for its onset (Allen, 2010; Letourneau et al., 2011). Others grappled with the uncertainty of whether symptoms were simply their partner's personality, or a sign of something more serious (Letourneau et al., 2011; O'Brien, 2016; Smith, 2013). Many advocated for education about Postpartum Depression during the prenatal period, emphasising that increased awareness of signs and symptoms would have allowed them to identify a problem earlier (Allen, 2010; Letourneau et al., 2012; Smith, 2013). With support from health professionals and increasing awareness, fathers' perceptions shifted; some realised that their partner did not choose to have PPD (Smith, 2013).

1.3.2.2 Dismissal of symptoms

Prior to receiving a diagnosis, participants frequently reported dismissing or minimising their partner's symptoms. In some cases, this resulted from their lack of awareness about PPD. Fathers instead attributed the symptoms to situational factors such as lack of sleep and hormonal imbalances (Letourneau et al., 2011; O'Brien, 2016; Smith, 2013). Some fathers did not recognise the symptoms of PPD until the partner once again seemed like her 'old self'. When the symptoms were attributed to behaviours under their partner's control (e.g. laziness, premorbid personality), this led to conflict, annoyance, and in some cases, a desire for divorce (Meighan et al., 1999; Smith, 2013). Even when their partner received a diagnosis of PPD, some fathers wondered whether it was in fact a premorbid part of her personality (O'Brien, 2016). Other fathers worried that addressing concerns with their partners would lead to conflict; they described their partners as emotionally sensitive during this time, and they did not want to appear judgemental or blaming (O'Brien, 2016). Stigma surrounding PPD was a barrier to both mothers and fathers in acknowledging a problem and recognising the need for help (Allen, 2010; Letourneau et al., 2012).

1.3.2.3 Experience of PPD symptoms

Fathers described differing experiences of their partner's Postnatal Depression. Many fathers noticed their partners becoming more emotionally sensitive and reactive, crying more frequently and feeling emotionally overwhelmed (Allen, 2010; Meighan et al., 1999; Siverns, 2012; Smith, 2013). Other fathers primarily described their partner's apathy, noticing a lack of interest in the child or her new role as a mother (Allen, 2010; Beestin et al., 2014). Fatigue or over-sleeping was also common and frequently identified by mental health professionals as a target for intervention (Letourneau et al., 2011; O'Brien, 2016; Siverns, 2012). Although less common, some

fathers were aware that their partner experienced thoughts or urges to harm themselves or their baby (Letourneau et al., 2011).

1.3.2.4 Stigma/Culture

Perceived stigma surrounding Postpartum Depression influenced fathers' understanding of PPD in a variety of ways. For some individuals, depression itself was not accepted in their culture, which made their partner's experience difficult to comprehend and acknowledge (Allen, 2010). Some fathers understood PPD as an illness that had to be kept hidden from others (Allen, 2010; Beestin et al., 2014). They described making efforts to hide their partner's symptoms, so that others did not see her as "crazy" or as a "bad mom" (p63; Allen, 2010).

1.3.3 Theme Two: Relationships

1.3.3.1 Relationship with baby

Shielding their children. Many fathers worried about the consequence that their partner's PPD might have for their infant and other children. One father described a stark contrast between the baby's response to both parents; the baby was irritable and teary with the mother and laughed and smiled with the father (Siverns, 2012). In some families, the older children asked their fathers why their mother did not want to spend time with them or join them on activities and other children expressed the belief that they were to blame (e.g. p10 Beestin, et al., 2014). The fathers described efforts they made to protect their infants and older siblings from the effects of PPD, such as being more involved with parenting, prioritising their own relationship with their child and sacrificing their own feelings in order to ensure a more peaceful household (Beestin et al., 2014; Siverns, 2012). For some fathers, there was an unexpected advantage to

this; by spending more time with their children, these fathers formed stronger bonds with their infants (Allen, 2010; Beestin et al., 2014).

Negative impact on fathering. In two studies, fathers described the negative impact of the mothers' PPD on their own parenting and relationship with their children. Witnessing depression and uncertainty about how to parent was unsettling; without their partner's confidence and support, their own uncertainty about how to look after a new infant increased (Allen, 2010). Other fathers noted that the additional time they were spending managing the difficulties in the mother-father relationship led them to feel psychologically and physically absent as a father (Beestin et al., 2014). These experiences were often accompanied by fathers experiencing symptoms of depression themselves. Some fathers were resentful of and disappointed by their fathering; what they anticipated as being a joyful and fulfilling experience, was instead experienced as devoid of joy, fun and fulfilment (Beestin et al., 2014).

1.3.3.2 Relationship with mother

Adjusting to a new partner. A common theme in many studies was the experience of adjusting to a new partner (Allen, 2010; Beestin et al., 2014; Letourneau et al., 2012; Meighan et al., 1999; O'Brien, 2016; Siverns, 2012). Fathers described feeling as though PPD had taken away the partner they knew; in their place was a partner that was more emotionally sensitive, vulnerable, fatigued and sometimes hostile. This was an isolating experience for many fathers; at a time when fathers were experiencing substantial stress, fear, worry and depression, they felt grief at losing the person that they previously relied on for support (Meighan et al., 1999; Siverns, 2012). They did not know their new partners and were unsure of how to interact with them. One father expressed fear at coming home from work because he was not sure whether he would meet his 'happy wife' or his 'angry pissed off wife' (p47; Allen, 2010). Many feared

their partner's rejection of them or described being emotionally and physically rejected by their partners (Beestin et al., 2014).

Walking on eggshells. Fathers experienced their partners as more vulnerable, emotionally sensitive and unpredictable. They were unsure of how to manage their partner's moods and feared that they might make her feel worse. At home, many fathers felt as though they were constantly walking on eggshells, uncertain of what to say and do and fearful of triggering conflict or making things worse (Allen, 2010; Letourneau et al., 2011; O'Brien, 2016; Siversns, 2012; Smith, 2004).

Resenting mother. There was often a dialectic between a desire to support their partner, and resentment (Beestin et al., 2014; Letourneau et al., 2011; Meighan et al., 1999; O'Brien, 2016; Siversns, 2012). Many fathers had taken on primary responsibility for household tasks, they continued to work full time and sacrificed many of their own needs in service of looking after their family. As these sacrifices took an emotional toll, many fathers began to resent having to also take care of their partners. One father resented his wife for the impact that her PPD was having on his children. He described witnessing his children feel rejected by their mother, and felt anger to the point of wanting to ask her to leave the family home (p10; Beestin et al., 2014). Other fathers described desperation for the experience to end, one father thinking at one point that his partner's suicide would achieve this aim (p4; Meighan et al., 1999)

Loss of good times. This theme represents the loss of fun, spontaneity and intimacy that fathers often experienced in their relationship during this time. For some, the exhaustion that resulted from caring for their infant and partner, as well as balancing their work responsibilities left fathers having little or no energy for spontaneity, casual conversation or intimacy (Allen, 2010; O'Brien, 2016). Some felt as though all

pleasurable aspects of life were shut down (O'Brien, 2016; Siverns, 2012) and they were in "survival mode" (p50; Allen, 2010). For other fathers, this disinterest in intimacy was more one-sided; participants sometimes made attempts at intimacy and were rejected continuously by their partner; this left them feeling hurt and rejected (Beestin et al., 2014). In some cases, fathers did not want to be around their partner's hostility and changing moods (Beestin et al., 2014)

1.3.4 Theme Three: Supporting Their Partner

1.3.4.1 Strategies to support mothers

Fathers tried to give support in many ways. Where mothers were hesitant about acknowledging a problem, partners played an important role in encouraging them to seek and accept help (O'Brien, 2016). In many instances, fathers tried to help by identifying helpful resources and gathering information about the disorder (Letourneau et al., 2011; O'Brien, 2016). Some fathers maintained that it was difficult to find the resources they needed. As the fathers grew more knowledgeable about the disorder, some began to educate family members and friends about their partner's experience and needs (Siverns, 2012). Where family visits added additional stress, fathers made efforts to limit these visits (Siverns, 2012). On a practical level, fathers took over more responsibility of household tasks and childcare duties. They sacrificed their own needs to take over tasks that their partner was no longer able to do (Meighan et al., 1999; O'Brien, 2016; Siverns, 2012; Smith, 2013). Many fathers described monitoring their partner's mood and interaction with their infant, taking over childcare when their partner appeared to need a break. Fathers also supported their partners sleep by adjusting their own sleep schedule and taking over night-time feedings (O'Brien,

2016; Siversns, 2012). In some cases this was explicitly recommended by health professionals.

1.3.4.2 Barriers to supporting mothers

A theme in every paper was that of feeling helpless (Letourneau et al., 2011; Meighan et al., 1999; O'Brien, 2016; Siversns, 2012; Smith, 2013). Fathers frequently expressed a desire to help, but were uncertain of how they could achieve this. Strategies they tried did not seem to work and sometimes their efforts resulted in frustration or anger on the part of their partner. They felt unable to understand what the mother was going through and lacked sufficient information about PPD in general.

In one case, the mother's PPD meant that she now needed him as an emotional support, something he never felt she had needed previously (O'Brien, 2016). He felt unable to provide this support as these skills were not in his repertoire and he tried to compensate in other ways such as taking on extra practical responsibilities around the house. Despite fathers' willingness to engage with their partners' treatment, they described being ignored by services and their partners' health practitioners (Letourneau et al., 2011).

1.3.5 Theme Four: Burden of PPD

1.3.5.1 Emotional burden

Prior to receiving a diagnosis, many fathers were frightened by the symptoms they witnessed, uncertain as to what was wrong. Once PPD was identified, they described worrying about their partner's well-being and the impact that PPD might have on the marital and mother-child relationship (Letourneau et al., 2011; Meighan et al., 1999; O'Brien, 2016). Their lack of preparedness made them fearful about their own ability to handle the situation or intervene effectively. Many fathers vividly described

experiences of their partner and infant crying, in some cases labelling these as “nightmarish” such as when their wife kicked a hole in the wall (p4; Meighan et al., 1999). Some feared that the experience would never end, and their partner would be forever changed. In one more extreme example, one father expressed fear that he would arrive home to discover his partner having died by suicide; he prepared himself daily for this event, reminding himself of the first aid skills he might need in this situation (p5; Meighan et al., 1999).

A portion of fathers identified as being depressed themselves or described symptoms of depression such as fatigue, irritability, sadness, anxiety and thoughts of harming themselves or their infant (Allen, 2013; Letourneau et al., 2011; Meighan et al., 1999; Siverns, 2012). In some cases, the father’s symptoms mirrored those of the mother; he would feel irritable when she felt irritable. This had impacted on their fathering in some cases, where children wondered aloud what was ‘wrong’ with their father (p12; Beestin et al., 2014). Many fathers felt hurt by their partners. On the one hand they recognised that their partner had a depressive disorder and needed help, on the other, they felt rejected and wounded by their partners who were described by words such as ‘apathetic’, ‘hostile’ or ‘aggressive’ (Beestin et al., 2014). Other fathers described the emotional impact of witnessing the person they loved suffer.

For many, the experience of living with a partner with PPD was isolating; practical difficulties such as location of family members, stigma, shame and a lack of support services available to men appeared to contribute to this feeling of isolation (Allen, 2010).

1.3.5.2 Unequal roles

Whether by choice or necessity, almost all fathers took on extra responsibilities at home, including feeding, shopping, spending time with the infant and household

chores (Allen, 2010; Beestin et al., 2014; O'Brien, 2016; Siverns, 2012). Where fathers felt unable to provide emotional support, taking on more practical responsibilities allowed them to feel they were helping (O'Brien, 2016). Many referenced their prior expectation that parenting and household tasks would be shared equally, and contrasted this to their experiencing of parenting for two. Over time, this became an isolating experience for some fathers; even when partners were physically present, they were perceived as being psychologically absent (p10 Allen, 2010; Beestin et al., 2014).

1.3.5.3 Sacrificing own needs

Fathers consciously sacrificed their own needs in service of supporting their family and partner. Sacrificing sleep to feed their infant took its toll on fathers, who described feeling continuously exhausted (O'Brien, 2016; Siverns, 2012). Many fathers reported sacrificing annual leave and work promotions and noticed their work performance suffer due to the competing demands of work and home responsibilities (O'Brien, 2016; Siverns, 2012). In some cases, they were threatened with job loss due to their inability to maintain a high standard of work (Siverns, 2012). Other fathers ceased engaging in their hobbies to maximise their time available for managing the household and taking care of their families (O'Brien, 2016). Many fathers spoke about 'walking on eggshells' with their partner, making concessions for how their partners treated them and sacrificing their own feelings in order to avoid conflict (Smith, 2013). One father noted that he had a relapse of depression specifically related to the intense pressure of working full-time and caring for his wife and infant at home (O'Brien, 2016). Nonetheless, fathers frequently noted that they did not feel they had an option; they saw their partner as struggling more than them and wanted to accommodate their partner's recovery from PPD (Meighan et al., 1999; O'Brien, 2016).

1.3.6 Theme Five: Supporting Fathers

1.3.6.1 Helpful resources

Overall, fathers highlighted specific strategies and resources that helped them to cope with their partner's PPD. It was rare for fathers to be included in professional services for their partner's depression, however one father noted the usefulness of receiving individual support for his mental health (Letourneau et al., 2011). Accessing information and advice from health care practitioners was also deemed useful (Siverns, 2012). Public health nurses were specifically identified as important sources of knowledge who gave useful concrete direction on how to approach difficulties (Siverns, 2012). Practical support from family members and close friends was identified as helpful, for example, delegation of tasks such as meal preparation, child care and household tasks (Letourneau et al., 2011). Having a break from the home environment was also experienced as beneficial, whether this was through simply being at work, purposefully getting outside for exercise or being physically separated from their partner (Letourneau et al., 2011).

Where the fathers experienced their couple relationship as strong, the security of their relationship was perceived as a coping resource (O'Brien, 2016). Similarly, some fathers noted that open communication with a partner helped them manage this difficult period in life (Allen, 2010). Social support was also crucial; having someone to talk to about their experience or receiving advice from friends who faced similar experiences was found to be uniquely beneficial in normalising their experiences (O'Brien, 2016; Siverns, 2012). Work environments were sometimes supportive in allowing fathers to take time off work to take care of their partner (Letourneau et al., 2011). Finally, fathers frequently noted that when their partners received support in

the form of support groups or input from mental health professionals, this also had a secondary positive impact on fathers (Letourneau et al., 2011).

1.3.6.2 Barriers to support

A common external barrier was the exclusion of men from services for women with PPD. Fathers frequently reported that health professionals did not inquire about their own mental health or include them in the recovery plan for their partner (Allen, 2010; Letourneau et al., 2011; Letourneau et al., 2012; Meighan et al., 1999). Many were unaware of services available for men, emphasising that the systems seemed exclusively targeted toward their partner. In terms of availing of social support, some fathers alluded to the lack of understanding that their friends and family had regarding PPD, the associated stigma that led to them hiding difficulties from their family, and others mentioned that their support network lived long distances away (Allen, 2010). Receiving support from their partner was rarely identified; most felt unwilling to place a further burden on their partner by addressing their own needs or discussing their experience. Some fathers added that the physical burden of supporting their family meant that they were too exhausted to seek out help for themselves (Allen, 2010).

1.3.6.3 Desired Resources

In almost all studies, fathers identified supports that they would have liked to have had. As noted earlier, fathers largely felt uneducated about PPD and had been unaware of the possibility of it occurring. Many suggested that couples should be educated about this prior to the birth of their infant, for example in pre-natal classes, in order to be prepared for any signs and symptoms (Allen, 2010; Letourneau et al., 2011; Smith, 2013). Fathers expressed a need for more information, including materials specifically targeted toward men (Allen, 2010; Letourneau et al., 2012). Some hoped that this

would provide them with direction on how to discuss PPD with their partner (Allen, 2010).

Many fathers reported that they would like to have someone to talk to about their experience, whether it be a mental health professional or other men going through similar experiences (Letourneau et al., 2011; Meighan et al., 1999; O'Brien, 2016). Some men expressed the desire to be part of a support group for couples or fathers (Allen, 2010); others reported unease at the idea of talking in this type of forum and instead suggested online forums or access to a male counsellor (Letourneau et al., 2011). The option to take time off work without using annual leave was identified as an important way of allowing them to better support their family (Letourneau et al., 2012).

1.4 Discussion

This review aimed to comprehensively examine qualitative studies investigating the experiences of fathers whose partners have Postpartum Depression. We identified six overarching themes, the clinical implications of which will be considered in turn.

1.4.1 Findings and Clinical Implications

A consistent theme, regardless of recency of the study, was a limited understanding of PPD. Prior to the birth, fathers were typically unaware that PPD was a possibility, leading to resentment, confusion and delays in identifying a problem. Even when PPD was acknowledged, fathers continued to have difficulty understanding their partner's experience and felt ill-equipped to help them recover. A lack of understanding can have negative implications for fathers' effectiveness in communicating with their partner (Bodenmann et al., 2008) and supporting recovery. Indeed, many fathers spoke about the struggle between wanting to protect their partner, and resentment for both

their partner's apathy or hostility and the increased burden on themselves. Partner-directed psychoeducation about PPD may alleviate some of the confusion fathers feel and address incorrect beliefs they may hold about their partner's behaviour (Goldstein, 1995).

The current findings also point to the desire of fathers to be included in interventions addressing PPD. It is well established that health professionals have traditionally worked primarily with mothers (Bateson, Darwin, Galdas, & Rosan, 2017; Humphries & Nolan, 2015) despite government policies and researchers encouraging otherwise (e.g. Kim & Swain, 2007; Kumar, Oliffe, & Kelly, 2017; Richardson, 2013). There is a growing evidence base supporting partner-inclusive interventions for maternal PPD (e.g. Alves, Martins, Fonseca, Canavarro, & Pereira, 2018; Pilkington, Milne, Cairns, Lewis, & Whelan, 2015) and this review is therefore timely. Cohen and Schiller (2017) recently developed a useful model for health professionals, providing guidance on the inclusion of fathers for the treatment of maternal PPD. This model recognises the couple relationship as an important agent in recovery and addresses many of the issues raised in the included studies. Psychoeducation, communication training and behavioural activation form the core of the model. It offers practical suggestions to increase fathers' understanding of PPD, provide them with guidance in improving communication with their partner, and increase their engagement in joint pleasurable activities.

Individual support for fathers may also be necessary, given the increased demands participants described. It was common for fathers to sacrifice their own needs to accommodate their partner's mental health. As a result, many experienced depression, isolation, exhaustion, and had difficulty maintaining a high level of work performance. This finding aligns with quantitative research which documents a higher

proportion of fathers experiencing symptoms of PPD when the mother also has a diagnosis (Paulson & Bazemore, 2010). Practical help from family and work environments, having someone to talk to, and being provided with information and guidance from health professionals were all experienced as helpful resources for fathers. Given the variation in preferences for type of support (e.g. support group, online forum, male counsellor), it is proposed that fathers are offered a range of supports from which to choose.

Another important implication is the impact of fathers' mental health on their parenting. Where maternal PPD negatively impacts mother-infant interaction, fathers can compensate by providing responsive and nurturing parenting experiences to their child. Moreover, positive paternal mental health is associated with better mother-infant interactions (Ray, 2017). While many fathers in these studies were motivated to compensate for their partner's PPD by spending more time with the infant, other fathers found that the deterioration in their mental health reduced the quality of their own parenting and father-child interactions. This lends weight to the idea that health professionals treating maternal PPD should routinely enquire about fathers' mental health, their ability to support their partner and to offer individual support where needed, given the potentially detrimental effects to the infant of having two parents with compromised mental and physical health (Ray, 2017). It also corresponds to quantitative evidence that fathers rate themselves, their marital relationship and their child more negatively when their partner has PPD (Milgrom & McCloud, 1996), and demonstrate less optimal father-infant interactions (Goodman, 2008).

1.4.2 Directions for Future Research

The number of studies on this topic indicates that there has been limited research directly investigating fathers' experiences of maternal PPD over the past two

decades. The studies were heterogeneous with regards to the number of years since their partners PPD and whether the partners had experienced previous pregnancies before developing PPD, limiting the generalisability of findings. Nonetheless, themes across studies were similar.

None of the included studies provided information on fathers' wellbeing prior to the onset of their partner's PPD. Prior mental health difficulties may have placed fathers at increased risk for experiencing depression themselves during this time, or indeed could have acted as a protective factor by motivating fathers to be aware of their own health and seek help where needed. This information would have been useful in distinguishing differences between fathers who appeared to cope well and not and identifying whether fathers' stress and burden precipitated the onset of their partner's PPD.

The included studies were conducted in the UK, the USA and Canada. Although themes were similar across studies, these countries are similar in terms of average income, and thus the experiences may not generalise to countries of lower-income or differing classifications of mental health.

Quality appraisal found that ethical issues were infrequently explored and the relationship between researcher and participants were at times not adequately addressed. This may be because journal word limits precluded detailed exploration of these factors. Interestingly, dissertations and doctoral theses typically scored higher in the quality assessment, increasing their likelihood of being included in the final review. Future research should employ a critical appraisal of the researcher-participant relationship, to reduce risk of coercion of research participants as well as increasing study validity.

1.8.2 Strengths and Limitations

To our knowledge, this is the first systematic review of studies investigating fathers' experiences of their partner's mental health. A strength is the thorough search strategy in line with PRISMA guidelines. The exclusion of studies considered to be of 'weak' quality may have increased the overall validity of research findings. However, the exclusion of qualitative articles based on quality is an on-going debate (Garside, 2014). Dissertations scored higher on quality assessment in this review, suggesting that potentially methodologically strong papers were excluded due to inadequate reporting as a result of journal word limits. Nonetheless, it was observed that the inclusion of weak quality studies would not have added new themes or insights to the overall findings.

Studies were excluded if they were not in the English language, which may have led to publication bias and exclusion of relevant studies from different cultures. Indeed, most participants identified as being Caucasian, and the exploration of stigma and shame was typically discussed by participants identifying with different cultures (e.g. Hispanic). This limits the generalizability of experiences outside of Western countries. Finally, full texts for four papers were not obtained due to a lack of response from authors or failure to provide contact information.

1.4.3 Conclusion

Traditionally, fathers have not been included in both research on maternal postpartum depression and clinical interventions for these women. There is a growing awareness however that maternal PPD is associated with a high rate of paternal PPD, and that a partner's mental health during this time has important implications for the mother's recovery and their infant's development. This systematic review highlights important

findings related to a fathers' experiences of their partners' PPD, emphasising the need for increased psychoeducation and partner-inclusiveness in health services.

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1.6 Declaration of Interest Statement

We declare no competing interests.

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1.9 Chapter One: Appendices

1.9.1 Appendix A: Psychology & Health guidelines

Psychology & Health

Aims and scope

Psychology & Health promotes the study and application of psychological approaches to health and illness. The contents include work on psychological aspects of physical illness, treatment processes and recovery; psychosocial factors in the aetiology of physical illnesses; health attitudes and behaviour, including prevention; the individual-health care system interface particularly communication and psychologically-based interventions. The journal publishes original research, and accepts not only papers describing rigorous empirical work, including meta-analyses, but also those outlining new psychological approaches and interventions in health-related fields.

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1.8.2 Appendix B: Search Strategy for Databases

Search strategy for each database

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MEDLINE	<p>"EXPERIENCE" OR DE "LIFE change events" OR DE "NARRATIVES" OR belie* OR account OR impact OR needs OR understand* OR view* OR experienc* OR perspective* OR attitude* OR narrativ* OR perception)</p> <p>(belie* OR account OR impact OR needs OR understand* OR view* OR experienc* OR perspective* OR attitude* OR narrativ* OR perception OR (MH "Life Change Events") OR (MH "Personal Narratives") OR (MH "Personal Narratives as Topic") OR (MH "Attitude") OR (MH "Attitude to Health")) AND (((post-partum OR post-natal OR peri-natal OR postpartum OR postnatal OR perinatal) AND (depress*)) OR (MH "Depression, Postpartum")) AND (couple* OR partner* OR man OR boyfriend* OR father* OR husband* OR dad OR daddy OR men OR paternal* OR spous* OR male OR (MH "Fathers") OR (MH "Spouses") OR (MH "Men") OR (MH "Male") OR (MH "Parents")))</p>
CINAHL	<p>(((post-partum OR post-natal OR peri-natal OR postpartum OR postnatal OR perinatal) AND (depress*)) OR (MH "Depression, Postpartum")) AND (belie* OR account OR impact OR needs OR understand* OR view* OR perception OR experienc* OR perspective* OR attitude* OR narrativ* OR (MH "Narratives") OR (MH "Life Experiences") OR (MH "Life Change Events") OR (MH "Attitude to Health") OR (MH "Attitude to Mental Illness")) AND (couple* OR man OR boyfriend* OR partner* OR father* OR husband* OR dad OR daddy OR men OR paternal* OR spous* OR male OR (MH "Fathers+") OR (MH "Spouses") OR (MH "Men") OR (MH "Male") OR (MH "Adoptive Parents") OR (MH "Biological Parents") OR (MH "Parents of Disabled Children") OR (MH "Parents"))</p>
Maternity & Infant Care	<p>(Experiences.de. OR Attitudes.de. OR Personal experiences.de. OR belie* or account or impact or needs or understand* or view* or experienc* or perspective* or attitude* or narrativ* or perception OR "Experiences (men)".de. OR "Attitudes (men)".de. OR "Attitudes (parents)".de. OR Beliefs.de.) AND (man OR boyfriend* OR partner* OR father* OR husband* OR dad OR daddy OR men OR paternal* OR spous* OR male OR men.de. OR male.de. OR Fathers.de. OR "Experiences (men)".de. or "Attitudes (men)".de. OR parents.de. OR partners.de.) AND (Postnatal depression - diagnosis.de. OR Postnatal depression.de. OR ((post-partum OR post-natal OR peri-natal OR postpartum OR postnatal OR perinatal) AND (depress*)))</p>
PsycINFO	<p>(belie* OR account OR impact OR needs OR understand* OR view* OR experienc* OR perspective* OR attitude* OR narrativ* OR perception OR DE "Attitudes" OR DE "Health Attitudes" OR DE "Narratives" OR DE "Life Experiences" OR DE "Experiences (Events)") AND (((post-partum OR post-natal OR peri-natal OR postpartum OR postnatal OR perinatal) AND (depress*)) OR DE "Postpartum Depression") AND (man OR boyfriend* OR partner* OR father* OR husband* OR dad OR</p>

	<p>daddy OR men OR paternal* OR spous* OR male OR DE "Spouses" OR DE "Human Males" OR DE "Couples" OR DE "Fathers" OR DE "Husbands" OR DE "Male Attitudes" OR DE "Parents" OR DE "Adoptive Parents" OR DE "Fathers" OR DE "Stepparents" OR DE "Surrogate Parents (Humans)"))</p>
<p>PsycARTICLES</p>	<p>(belie* OR account OR impact OR needs OR understand* OR view* OR experienc* OR perspective* OR attitude* OR narrativ* OR perception) AND (((post-partum OR post-natal OR peri-natal OR postpartum OR postnatal OR perinatal) AND (depress*))) AND (man OR boyfriend* OR partner* OR father* OR husband* OR dad OR daddy OR men OR paternal* OR spous* OR male)</p>
<p>Psychology & Behavioral Sciences Collection</p>	<p>((post-partum OR post-natal OR peri-natal OR postpartum OR postnatal OR perinatal) AND (depress*)) OR DE "POSTPARTUM depression" OR DE "POSTPARTUM depression diagnosis") AND (man OR boyfriend* OR partner* OR father* OR husband* OR dad OR daddy OR men OR paternal* OR spous* OR male OR couple* OR DE "COUPLES" OR DE "FATHERS" OR DE "ABSENTEE fathers" OR DE "ALCOHOLIC fathers" OR DE "BIRTHFATHERS" OR DE "HETEROSEXUAL fathers" OR DE "LGBT fathers" OR DE "MENTALLY ill fathers" OR DE "MIDDLE-aged fathers" OR DE "NONBIOLOGICAL fathers" OR DE "STAY-at-home fathers" OR DE "STEPFATHERS" OR DE "WORKING fathers" OR DE "HUSBANDS" OR DE "MEN" OR DE "SPOUSES" OR DE "HUSBAND & wife" OR DE "MARRIED men" OR DE "PARENTS" OR DE "ABSENTEE parents" OR DE "ABUSED parents" OR DE "ABUSIVE parents" OR DE "ADOPTIVE parents" OR DE "AGING parents" OR DE "ATTENTION-deficit-disordered parents" OR DE "BIRTHPARENTS" OR DE "BISEXUAL parents" OR DE "BLIND parents" OR DE "CO-parents" OR DE "COLLEGE student parents" OR DE "CUSTODIAL parents" OR DE "DEAF parents" OR DE "DIVORCED parents" OR DE "FATHERS" OR DE "FIRST-time parents" OR DE "FOSTER parents" OR DE "GRANDPARENTS as parents" OR DE "HETEROSEXUAL parents" OR DE "LGBT parents" OR DE "LOW-income parents" OR DE "MINORITY parents" OR DE "NATIVE American parents" OR DE "OLDER parents" OR DE "PARENTS of AIDS patients" OR DE "PARENTS of LGBT people" OR DE "PARENTS of alcoholics" OR DE "PARENTS of autistic children" OR DE "PARENTS of celebrities" OR DE "PARENTS of children with disabilities" OR DE "PARENTS of chronically ill children" OR DE "PARENTS of college students" OR DE "PARENTS of dyslexic children" OR DE "PARENTS of entertainers" OR DE "PARENTS of gay people" OR DE "PARENTS of intersex children" OR DE "PARENTS of multiple births" OR DE "PARENTS of overweight children" OR DE "PARENTS of people with disabilities" OR DE "PARENTS of problem children" OR DE "PARENTS of sick children" OR</p>

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1.8.3 Appendix C: Quotations & Author Interpretation by Theme

Panel 1: Understanding PPD

Lack of awareness

Quotations from participants:

- So, it would have been helpful to be familiar with some of the symptoms so we knew what was happening when it started happening (p 55; Allen, 2010)
- I thought I was doing a good job, and suddenly here it is and I'm going is it something that I didn't do or did too much of? (p43; Letourneau et al., 2011)

Interpretation of study authors:

- He wonders if her inability to handle the care of the household and the boys is related to her postpartum depression or if it is related to an aspect of her personality that he has felt has always been present... (O'Brien, 2016)
- They began to recognise that their partner did not choose to have postpartum depression, but they needed support, understanding and encouragement to work through its effects. (p58; Smith, 2013)

Dismissal of symptoms

Quotations from participants:

- I just thought she was being lazy. (p52; Smith, 2013)
- I thought it just meant that there was a little bit of a chemical imbalance because of your hormones after you had the baby. (p61; Siverns, 2012)

Interpretation of study authors:

- Thus, some fathers spoke of minimising their partner's symptoms by attributing her mood changes to the stress of having a new baby (p44; Letourneau et al., 2011)
- Four of the father's admitted that they did not know if this was the new woman their wife had become and thought that she would always maintain the symptoms the PPD was causing (p48; Allen, 2010)
- Instead, couples engaged in this process of dismissal because there was a legitimate concern that admitting symptoms and concerns aloud would make matters worse by seeming judgmental or burdensome. (p120; O'Brien, 2016)
- Several fathers reported that the stigma associated with PPD significantly contributed to their partner's denial of the issue, which often proved to be another barrier to support. (p45; Letourneau et al., 2011)

Experience of PPD symptoms

Quotations from participants

- [My wife's] also a lot more emotional. The tiniest little argument can turn into a huge fight on a dime...(p50; Siverns, 2012)
- She would call sobbing and say 'You've just got to come home...I can't take it another minute' (p4; Meighan et al., 1999)
- She got to the point where she wouldn't get out of bed, erm, she wouldn't eat, she wouldn't play with the kids. The kids would go in and give her a

love and a kiss, and then she'd just turn over and go back to sleep... (p10; Beestin et al., 2014)

Interpretation of study authors

- The most prominent signs of depression that the fathers included in the study expressed about their partner were mood swings, not wanting to take care of the new baby, anxiety, crying, feeling overwhelmed, fatigue and having images or dreams of hurting the baby. (p46-47; Allen, 2010)

Stigma/Culture

Quotations from participants

- I'd come straight home and I'd be looking after [daughter], I'd change her, clean up the house, tidy whatever, and then I'd have to go back [to work], because she [partner] wouldn't, she wouldn't ever, she didn't do it (...) if I didn't come home and do it and people came in and saw that, then they'd know that something was wrong. (p11; Beestin et al., 2014)
- It's not just freaky people unbalanced to begin with who might feel this (p44; Letourneau et al., 2011)

Interpretation of study authors

- The participant from the Hispanic culture reports that depression is not accepted or spoken about. This made it more difficult for him to accept and understand what his wife was going through. Further, it isolated him from his friends and family because the subject was one that kept "in" the family (p52; Allen, 2010)

Panel 2: Relationships

Relationship with Baby

Shielding children

Quotations from participants

- I did my best to ... to shield him from the difficulties that my wife was having...think it's important that he eventually know about it but uh I also want him not to feel uncomfortable in any way because of the anxiousness that's going on in the household. (p56; Siverns, 2012)
- I didn't want the children to suffer... I tried to protect them...It was part of the weight I was carrying (Meighan et al., 1999)

Interpretation of study authors

- Most frequently men adapted by accepting their partner's absence and the loss of joint parenting, and by shifting their priorities to the father-child relationship. (p14; Beestin et al., 2014)
- Interestingly, five fathers reported that the relationship with their newborn was positively affected due to a "role shift". The fathers that felt this way reported that, due to their wife's depression, they were forced to take on more "traditional" roles of the mother and spend more time with the

newborn. This additional time they spent with their new-borns fostered a more positive relationship (p50-51; Allen, 2010)

Negative impact on fathering

Quotations from participants

- I didn't feel like I knew what to do and so when she felt like she didn't know what to do, then I really didn't know what to do. (p46; Allen, 2010)
- I just don't wanna be around anyone and the kids will be like, saying like 'daddy's in a really bad mood, what's wrong with you daddy?' and I'm mumbling and being grumpy and whatever, but it's a case of it's just too much. (p12; Beestin et al., 2014)

Interpretation of study authors

- Becoming preoccupied by the difficulties within the adult relationship meant that some men felt they were psychologically and physically absent as fathers. (p12; Beestin et al., 2014)

Relationship with mother

Adjusting to a new partner

Quotations from participants:

- I had never thought of her as anything less than totally put together before, so this was a totally new feeling for me. (p145; O'Brien, 2016)
- I've lost my wife now...and I don't mean physically but mentally...I didn't know if she was going to make it back from that far away planet that she was on. (p5; Meighan et al., 1999)

Interpretation of study authors

- In addition to expressing guilt, powerlessness, and anguish, participants grieved the loss of the partner that had once known. (p55; Siversns, 2012)
- All eight fathers' felt like they wanted their partners back (p48; Allen, 2010)
- Finally, fathers reported that what they needed most was to have healthcare professionals bring their partners "back" from PPD ($n = 5$) (p74; Letourneau et al., 2012)

Walking on eggshells

Quotations from participants:

- I've walked on eggshells tons of times, where you just don't want to really say what you're feeling. (p49; Siversns, 2012)
- I just bit my tongue a lot because I could see that Alice wasn't doing well. (p143; O'Brien, 2016)
- If you said something it made it worse so if you didn't say something; only made it worse.... God forbid you mention postpartum depression. If you even just say the word postpartum depression a bomb goes off...it was like World War II. (p55; Smith, 2013)
- ...we would actually just walk around the house on eggshells wondering if (wife) is going to have one of these episodes and what is the effect going to be on her and our little guy (p44; Letourneau et al., 2011)

Interpretation of study authors:

- The father's felt that their wives were not the person that they knew and they didn't know how to interact for fear of making their symptoms worse. (48; Allen, 2010)

Resenting mother

Quotations from participants:

- ...her crying was just driving me nuts. Which is stupid because really the feeling inside is you want to protect her and make her feel better, but at the same time what is coming up is holy cow, I've just got to shut her up (p44; Letourneau et al., 2011)
- I would come home and I'm ... not only would I have to help looking after the baby, but I would have to deal with the stress of her all night. (p54; Siversns, 2012)
- I thought her suicide would be an answer, then I felt guilty for [having] those feelings. (p4; Meighan et al., 1999)

Interpretation of study authors:

- It created a situation where David was feeling the stress of beginning a new career, being sleep deprived and still needing to shoulder most of the household concerns. David saw Donna as someone who was struggling and needed help, however he also resented her and the position her was being put into.(p160; O'Brien, 2016)
- For instance, the disengaged presence of Bill's wife was 'more of a hindrance than a help' and he 'nearly packed her bags' as her rejection of the children, and their misplaced guilt ('the kids would say 'is it something we've done?')' (p10; Beestin et al., 2014)

Loss of good times

Quotations from participants:

- I would approach by simply just saying a hand on her shoulder or rub[bing] her back and wait[ing] to see if there was any reaction...in those first 3 or 4 years, 99% of the time there was no response....[I would] swallow that hurt, that rejection...I remember times of sobbing and trying not to let her hear it. The head says, I understand that there is a medical reason or a hormonal reason, it's not because she doesn't love you, but for the heart and those natural desires that a man should have for his wife to be rejected continually – that's a tough one (p5; Meighan et al., 1999)
- It's been 5 months of, you know, really not too much spontaneity. (p37; Siversns, 2012)
- I just had feeling like life was shut down for two years. (p45; Allen, 2010)

Interpretation of study authors:

- There is also a lack of any casual conversation between them now. This is something that David saw as a hallmark of their lives before they had children. They truly enjoyed sitting and talking with each other. They no longer have this and David feels that this is directly related to Donna's

postpartum depression and her need for control over every aspect of her life. (p166; O'Brien, 2016)

- He felt that the destructive impact, which stemmed from the deterioration of the partner relationship and his subsequent desire to be away from the hostility, meant that they had no 'good times' as a family (p11; Beestin et al., 2014)

Panel 3: Supporting their partner

Strategies to support mother

Quotations from participants.

- It would be 2:00 in the morning that's usually when it was the worst, I'd say...let me have him for a little bit and you just kind of calm down a little bit. And she would kind a gain her senses a little bit. I've learned what babies [do that] kind of trigger her and what I can do to help so I tried to help as best I could. (p53; Smith, 2013)
- I decided that, you know, she ... if she was going to start feeling better, she needs to get sleep at night. Uh, so for the first three months she would go to bed at 9, 10 o'clock and I would stay up and I would feed our daughter at about 11:30 and I would sleep in another room or sleep on the couch. And then I would get up 3-1/2 hours later and I would feed her again. (p53; Siverns, 2012)

Interpretation of study authors

- Partners were key players in acknowledging of the depression and making accommodations to aid mothers in the process of recovering from their postpartum depression. (p135; O'Brien, 2016)
- Most fathers tried to be self-reliant, describing different strategies for identifying PPD resources for their partners: the most common of which was 'digging for information'. (p44; Letourneau et al., 2011)

Barriers to supporting mother

Quotations from participants:

- She will probably tell you that I am not there for her on some emotional level that she needs me to be. That just isn't who I am and I have never been that person. (p148; O'Brien, 2016)
- The hardest thing was that I couldn't fix it. Nothing that I could do or was doing at the time was helping her. (p4; Meighan et al., 1999)

Interpretations of study authors:

- Many participants expressed feelings of helplessness in the face of their partner's suffering (p55; Siverns, 2012)
- The fathers included in the study, felt that they were completely left out of the process once their partners were diagnosed. They want to be included so that they can help too. (p63; Allen, 2010)

- Some fathers accompanied their partners to treatment, and while they wanted to contribute to their partner's care, health professionals excluded them from the treatment process (p45; Letourneau et al., 2011)

Panel 4: Burden of PPD

Emotional Burden

Quotations from participants

- I might find her dead. I had to condition myself every day when I got home...if you go in and she's on the floor, call 911, check for vital signs, try to remember those things in first aid (p5; Meighan et al, 1999)
- ...it's hard to see the person you love suffer that much (p54; Siversns, 2012)
- I have been really fed up and I just don't want anyone around me (...) I just don't wanna be around anyone and the kids will be like, saying like 'daddy's in a really bad mood, what's wrong with you daddy?' and I'm mumbling and being grumpy and whatever, but it's a case of it's just too much. (p12; Beestin et al., 2014)

Interpretation of study authors

- Partners also expressed fear or worry for their partners and relationship uncertainty (p44; Letourneau et al., 2011)
- There was a sense of relief that things that were hidden were being revealed, but there was also a sense of fear and concern about how to handle what had come to light. (p128; O'Brien, 2016)
- ...the fathers felt emotionally wounded, hurt and had a great deal of difficulty withstanding the hostile environment that their home had turned into (J. K. Smith, 2013)

Unequal roles

Quotations from participants.

- Especially those first couple of months I think I took on a huge ... a huge role. You know, leaving work early and like really just focusing on them and putting everything else kind of on the backburner. (p53; Siversns, 2012)

Interpretation of study authors

- Rather, participants emphasised the unexpected, and isolating, experience of taking on the duties of two parents. (p10; Allen, 2010)
- They expected, that for the most part, Bob would continue with taking care of the household and Betty would take care of the baby. However, as they felt the pressure of their roles and they developed concerns related to Betty's depression, more and more of the responsibilities fell on Bobby's shoulders (p224; O'Brien, 2016)

Sacrificing own needs

Quotations from participants:

- It was up to me to hold things together...I had to take care of them...my needs were last. (p4; Meighan et al., 1999)

- When did I get a break? But I didn't ask for it. I couldn't ask for it. Alice needed me to take over and so I did. (p143; O'Brien, 2016)

Interpretation of study authors:

- Most of the participants described the pull between these two areas of responsibility and the overwhelming exhaustion they felt while trying to meet the needs of their partners at home and their superiors and colleagues at work. In fact, some related the toll that their exhaustion was taking at work (p38; Siverns, 2012)
- They tried to communicate with their partners as well as sacrificing time and energy to care for the new baby, other children, and maintain the home while trying to keep the situation with their significant other from escalating out of control. They made concessions that were aimed at keeping their partner calm and rational. (p53; Smith, 2013)

Panel 5: Support for Fathers

Helpful Resources

Quotations from participants:

- Just get out and separate myself [from their partners and situation] (p44; Letourneau et al., 2011)
- P: Our public health nurse [has] come to ... visit a couple times now. And it's just been ... like someone opening up the blinds to the windows and ... light coming through and just saying, "Hey, listen, you know, this is what you have." Or, "This is what you're dealing with. And this is how to deal with it." (p64; Siverns, 2012)

Interpretation of study authors

- Many of the father's included in the study felt that open communication with their partners was essential in getting them through this difficult period. (p58; Allen, 2010)
- He was surprised when Gabby wanted to become more involved at church, but he was also relieved, because he was able to fulfil his need to be more social and found a source of support all at the same time. (p210; O'Brien, 2016)

Barriers to support

Quotations from participants

- I felt like I was out there all on my own, without anybody to guide me, or anybody to talk to (p6; Meghan et al., 1999)
- There's nothing in place for ... for the dads. I know for me I felt very on my own this whole time ... 'Because I don't want to burden my wife with, you know, how I'm feeling ... And again family just doesn't understand ... (p66; Siverns, 2012)
- I just didn't have, I mean part of it is that you don't have any time and you're so out of energy, you don't have time to wade through the Yellow Pages or

do a big long Internet search on where can I go for help with this. (p57-58; Allen, 2010)

- They never once asked about me... (p77; Letourneau et al., 2012)

Interpretation of study authors

- Societal views regarding parental-gender roles reinforced many fathers' attitudes and posed a barrier to support. While everyone asked the fathers about their partners and the baby, no one asked the fathers about how they were dealing with the transition to parenthood. (p45; Letourneau et al., 2011)

Desired Resources

Quotations from participants

- I had hoped for a little more support on the caregiver end. It is an absolute illness. (p6; Meighan et al., 1999)
- Somebody should be there talking about this we shouldn't wait until it happens and then have an intervention, should be prevention (p44; Letourneau et al., 2011)
- I would want to know the main basic thing, I mean, explain to me what the heck it is. Obviously. I mean you probably can explain the basics, but also what it is? What should you expect of it? (p63-64; Allen, 2010)
- I think it would have been beneficial to have like a class...for the fathers to go to at the hospital you are going to be at or something like just saying these are like the identifying traits of a woman with depression. (p57; Smith, 2013)

Interpretation of study authors

- Fathers also desired access to information about PPD ($n = 11$). They believed that this information should be more readily available to new parents and the information that is currently available should feature fathers more centrally. (p74; Letourneau et al., 2012)
- Fathers in the study expressed gratitude when they saw how beneficial these groups were for their partners and they wished that they could have also been involved in those structured groups. (p211; O'Brien, 2016)

2 Chapter Two: Empirical Study

Title: 'Treated as a person, not a case': Exploring meaning-making in an Open
Dialogue informed mental health service

Prepared in accordance with submission guidelines of *Journal of Mental Health*

(Appendix A)²

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inserted in the text for ease of examination

**‘Treated as a person, not a case’: Exploring meaning-making in an
Open Dialogue informed mental health service**

Niamh Doyle^{a*}, I. Twamley^b and M. Dempsey^a

^aSchool of Psychology, University College Cork, Cork, Ireland; ^b

Correspondence to *Niamh Doyle, School of Psychology, University College Cork,
Ireland, Niamh.doyle5@hse.ie

‘Treated as a person, not a case’: Exploring meaning-making in an Open Dialogue informed mental health service

Background: Against a tradition that has given preference to the ‘expert’ view of practitioners, a growing number of former service users have campaigned for mental health services to restore personal meaning to their mental health. Open Dialogue is an approach to mental health services that facilitates shared meaning-making among service users and professionals. *Aims:* This study investigated how individuals currently engaged in an Open Dialogue informed mental health clinic in Ireland made sense of their mental health. *Method:* Six individual semi-structured interviews were conducted and analysed using interpretative phenomenological analysis. *Results:* Two superordinate themes and related subthemes are discussed: ‘The Context of Meaning-Making: Relationships and Conversations’ and ‘New Meanings’. *Conclusions:* The participants provided evocative accounts of meaning-making within an OD informed mental health service, drawing from experiences of non-dialogical services to make valuable comparisons. The narratives provide evidence to support OD as a humanising approach to mental health services, which facilitates, rather than imposes meaning, and may lead to relational and individualised narratives that reduce self-blame.

Keywords: qualitative methods; interpretative phenomenological analysis; meaning; mental health; mental health services; open dialogue approach

2.1 Introduction

This paper considers how people make sense of their mental health through an Open Dialogue (OD) informed mental health service: an innovative approach, developed in Finland in 1980s, that emphasises shared meaning-making and the coexistence of multiple perspectives (Seikkula et al., 2003).

How we make sense of our mental health depends on meanings that are culturally available, as well as how others respond to our emerging ideas (Johnstone et al., 2018). Within the field of mental health, primacy has traditionally been given to

the views of ‘expert’ mental health professionals. Many services users have noted that their personal experiences and perspectives are marginalised and they are treated as if they are incapable of understanding their own mental health (Cohen, 2008). Bakhtin (1999) considered the assumption of only one valid perspective a ‘monological’ approach. In the context of power discrepancies between service users and practitioners, the task of defining meaning has almost exclusively fallen to practitioners (Guilfoyle, 2003).

A growing number of former service users are now campaigning for mental health services to restore personal meaning to their mental health, and to “take back authorship of their stories” (Dillon & May, 2002, p.16). In mental health services in Ireland and abroad, this has translated to the implementation of ‘recovery’ principles (Department of Health, 2006). Recovery-oriented services encourage equal partnership between service users and practitioners, and emphasise individual and personal narratives (Barker, 2002). There are mixed reports regarding the implementation of these principles: many service users feel that they are implemented as a tick-box process, without real impact on service quality (Harper & Speed, 2012; O’Keeffe et al., 2018; Pilgrim & McCranie, 2013; Weinstein, 2008). In a recent United Kingdom based qualitative study by Brown (2019), service users noted that despite the recovery orientation of their mental health service, they felt pressured to subscribe to, and act according to, the views of practitioners. It may be that a radical shift in service organisation is needed to effect change at a deeper level.

OD adopts elements of Family Therapy, Narrative Therapy and Needs Adaptive Treatment. Its principles of mental health service delivery prioritise immediate help, a social network perspective, flexibility and mobility, responsibility, tolerance of uncertainty and dialogism (Seikkula et al., 2003). Among the key

differences to traditional mental health teams is the fact that all discussions and decisions made about a person take place in their presence. The service user and their network are privy to the team's reflective discussions which expose them to new perspectives. In contrast to monologism, dialogic practice aims not to impose a new logic or 'expert' opinion of a problem, but to facilitate dialogic conversation where shared and multiple meanings can emerge (Anderson, 1995). Dialogue itself is considered an intervention, the means through which change can occur. Indeed many service users have documented the power of this process (Grant, 2015; Romme, Escher, Dillon, Corstens, & Morris, 2009; TED Talk, 2013; Waddingham, 2013). OD is currently being piloted trans-diagnostically in countries including Ireland, Germany, United Kingdom, and America.

An emerging evidence-base suggests considerable success of OD for the treatment of first-episode psychosis and schizophrenia (Seikkula et al., 2006). No research, to our knowledge, has specifically addressed meaning-making in an OD informed mental health service.

2.1.1 Research Question

This study uses a qualitative design to consider how individuals make sense of their mental health through OD-informed treatment meetings.

2.2 Method

2.2.1 Research Context

This study takes place in the context of an adult mental health service in Ireland that is informed by the principles of OD and utilises a dialogical approach routinely. The "Open Dialogue" clinic operates one day a week from a community location, thereby

compromising the flexibility and mobility to respond to crises that characterise a 'pure' OD approach.

2.2.2 Procedure

After institutional ethical approval was granted (Appendix C), eligible service users were identified by their mental health team, who provided them with a study flyer and information sheet (Appendix H and I). Inclusion criteria were: active involvement in the OD informed service and a minimum of 4.5 hours face-to-face contact completed with their team (i.e. three OD meetings, which is the average clinic contact). Eight participants opted in to be contacted by the researchers and were subsequently invited to take part in an interview at a time convenient to them. Following several unsuccessful scheduling efforts, two potential participants were excluded from the study. It was emphasised to participants, verbally and on the information sheet, that their decision to participate in the study would not affect the mental health care they received and that they could withdraw from the study up to two weeks post interview. Participants were interviewed in the OD clinic by the primary researcher; a Trainee Clinical Psychologist (TCP) with no previous involvement with the service.

Written, informed consent was required from each participant prior to engaging in the study. Thereafter, each participant completed a brief, demographic questionnaire (Appendix F) before the interview began. Six 60 to 80-minute, semi-structured, audio-recorded, interviews were conducted. Typically, the interview started with the following: "tell me how you came to Open Dialogue?". Subsequent questions explored participants' understanding of their mental health and their experiences of meaning-making in the OD informed service, as well as in previous services (Appendix G).

2.2.3 Analysis

Interviews were transcribed verbatim, with identifying information omitted. Interpretative Phenomenology Analysis (IPA) following guidelines from Smith, Flowers and Larkin (2009) were used in analysing the data. IPA acknowledges the researcher's conceptions as an important contributor to the interpretation of data and construction of themes. The double hermeneutic (Smith & Osborn, 2007) involves the researcher making sense of the participants' attempts to make sense of their experience. The researcher began by immersing herself in the data: reading and re-reading the transcripts and listening to the recorded interviews. Anything striking about the data or the process of interviewing was noted. Line-by-line coding was conducted to describe the content of the participants' words, staying close to their initial wording and meanings. Comments were noted about language use and language punctuation including pauses and laughter (see Appendix L).

Data were then analysed at a more conceptual level to derive overarching meanings from the text. At this time, the researcher drew upon her own professional knowledge to note questions of interest. Emergent themes for individual transcripts were developed by drawing connections and patterns across codes. Next, emergent themes were analysed together and grouped into sub- and superordinate themes. The researcher repeatedly referenced the research question and transcripts to ensure that the analysis fit the themes of the larger data set and research aims (Smith, 2001).

2.2.4 Reflexivity

IPA is intersubjective and therefore influenced by the researcher's bias. An inability to be open to the data poses a threat to the validity of qualitative research and it is crucial to state the research interests of the researcher (Smith, Jonathan & Osborn, 2007). The TCP has worked within traditional mental health services in the public

service for three years and has an interest in alternative approaches to delivering mental health care.

For quality assurance, two co-researchers checked the coding process of a sample of transcripts. Coding was revised following discussion to ensure that the process reflected the narratives of the participants rather than any bias of the researcher's interests. The same process was repeated for the final list of themes, whereby the researchers challenged the interpretations made and referenced back to the original transcripts.

To strengthen the credibility of presented findings, disconfirming case analysis was employed following the identification of themes (Smith et al., 2007). The researcher reviewed the transcripts again to actively seek 'disconfirming instances' where the data did not fit the identified themes. Wherever found, this was reported in presented findings. A paper trail of the analysis was also kept, allowing for all stages of the analysis to be retraced if required.

2.2.5 *Participants*

Five women and one man were interviewed (mean age = 26.5, age range: 20-35). See Table 1 for demographic information.

Table 1: Demographic information

Pseudonym	Age	Years of involvement with OD	Previous involvement with services
Olivia	24	1	General Practitioner (GP); psychiatry; social worker; support group
Edel	25	2	GP; school counsellor; sexual abuse counselling; group therapy; CBT therapy; inpatient in mental health hospital
Mark	30	2	GP; psychology
Anna	35	3	GP; counselling; CBT therapy; psychiatry; social work; inpatient in mental health hospital; reiki

Amy	25	2	GP; sexual abuse counselling; counselling; school counselling
Lauren	20	3	GP; counselling; psychiatry

2.3 Results

This study explored how individuals made sense of their mental health difficulties through an OD informed mental health service. Two super-ordinate themes, with six subthemes, were identified: *The Context of Meaning-Making: Relationships and Conversations* and *New Meanings* (see Table 2).

Participants contrasted their experiences in the OD informed service, to that of experiences with alternative mental health professionals listed in Table 1. For the purposes of simplicity, these are referred to within the analysis as experiences in ‘non-dialogical services’, however it is important to note that it encompasses a wide variety of experiences within and outside of the public mental health services.

Table 2: Description of Superordinate Themes and Subthemes

Superordinate Theme	Subtheme	Description
The Context of Meaning-making: Relationships and Conversations	Treated as a person, not a case	Participants’ identity in mental health services; Having a full identity in OD, opposed to ‘being’ one’s mental health.
	My voice is valued and equal	Having one’s voice considered equal to that of professionals; encouraged to contribute to shared meaning-making
	Generating multiple perspectives	Exposure to multiple perspectives of mental health through a polyphonic approach
New Meanings	Meaning through a relational and systemic lens	Diversity of meanings made; relational and systemic explanations
	We’re all just human beings	Acknowledgement of common humanity and shared suffering; connection to others
	Trusting my own voice	Ownership over one’s interpretation and recovery

2.3.1 The Context of Meaning-Making: Relationships and Conversations

Within OD, meaning-making is understood to emerge through dialogic conversation and collaborative relationships (Anderson, 2012). Thus, to understand how individuals make sense of their mental health, it is pertinent to consider the conversations and nature of the relationships between participants and their OD informed team. This superordinate theme captures the relationship between participants and their team, as well as the conversations wherein new meanings were created.

2.3.1.1 Treated as a person, not a case

There was a dominant theme among participants that they felt humanised by the OD informed approach. The consistency in team members within the OD approach provided Mark with a feeling of being ‘known’. This enhanced his sense of self. On one occasion, an unfamiliar professional joined one of his treatment meetings, and the experience contrasted sharply: “Because Kelly and Patricia know my story from back to front like so ... I feel like I'm actually, or that they're talking about an actual person as opposed to a case”.

For Lauren, Amy, and Edel, it was the breadth of conversation that humanised interactions:

It's not robotic. You don't have certain questions you know like with a psychiatrist they say, how are you feeling? What's going on today? Has anything changed? [...] we spoke about school, we spoke about college, we spoke about the future and the voices. (Lauren)

This was linked by Amy and Edel to a less restrictive interpretation of their mental health:

Because I can chat about having a bad day. It doesn't have to be all about the past, it doesn't have to be major crisis. If you're going to counselling, it's because there is something majorly wrong in your head. (Amy)

2.3.1.2 *My voice is valued and equal.*

Participants described the collaborative nature of meaning-making within the OD informed service, whereby they felt like equal participants in making sense of their mental health. Repeatedly through the data, they contrasted this experience with previous experiences of non-dialogical services. Amy conveys a transfer of power regarding meaning-making, from professionals back to service user, “they [individual counsellor] could be writing down ‘psycho’ ... whereas they’re saying: ‘what would you say?’”. This quote points to both the transparency inherent in an OD approach and the value placed on clients’ perspectives. Dialogic practice involves ‘witness’ versus ‘aboutness’ practices in clinical meetings (Shotter, 2006), which is further evidenced in this quote from Anna: “they’re not talking about you behind a door [...] you’re in the room and they’re discussing you”.

Treatment meetings, experienced as informal and reciprocal, were described as a “conversation” (Edel) and “a chat” (Mark). There was felt agency over the content of discussions that contrasted with the one-way nature of interactions experienced in some non-dialogical services:

I got to choose what to talk about. So I think with a psychiatrist it would be a case of this, this and this... And I wouldn’t get any input, I’d just have to answer the questions and that’d be it. (Lauren)

Participants trusted that their contribution would be accepted without judgement and this facilitated safety to explore difficulties openly. Lauren aptly

conveys this trust in the quote: “I could talk about anything and it’s not going to be judged”.

2.3.1.3 *Generating Multiple Perspectives*

An emphasis on generating multiple perspectives demonstrated to some participants that there are many lenses through which to view a problem. This is conveyed by Olivia:

With a one on one counsellor they can get very fixated on what they think or they might have certain beliefs and look at things in a certain way and it’s good that they [OD team] have a contradicting opinions sometimes because the more points of view you have the better. There’s countless numbers of ways to look at most situations. (Olivia)

By encouraging multiple and contradicting viewpoints, the participant is free to choose an interpretation that fits for them. Edel describes this process as “two angels on my shoulder”, portraying an image of multiple compassion guides in her journey of meaning-making. The absence of a ‘united front’ approach typical to traditional mental health services (Johnstone et al., 2018) meant that a single interpretation was not imposed, and thus participants did not seek solutions: “It’s not necessarily a place I can seek answers” (Mark). It also allowed participants to consider their own and their team’s perspectives, without searching for a single truth.

She was kind of going oh but you know you’re very sensitive. And I was like yeah I know, but it can be a bit of both. It can be like it wasn’t a very nice experience, and I’m sensitive [laughs] you know what I mean? It can be like not just one or the other. (Edel)

The appreciation of multiple perspectives of mental health is reflective of the dialogic approach in OD.

2.3.2 *Creating New Meanings*

Participants expressed ownership over their complex, individualised narratives of how they understood their mental health, that moved away from self-blame and connected them to other people.

2.3.2.1 *Trusting my own voice*

Five participants conveyed a sense of ownership over their individual narratives. Mark illustrates this in the following excerpt: “My story is my story and how I have used this space has been the way that I use the space”. Lauren links the growing trust in her own voice, with the absence of being provided with an answer:

They couldn't really say this is what it is and we can get rid of it for you [...] the more I spoke about it the more I understood what was going on, that I knew that in that way I could help myself. (Lauren)

There was an acknowledgment that making sense of mental health is complex and meaning may never be finalised, either for professionals or service users. The idea of ‘unfinalisability’ is central to dialogism, wherein new meanings can always emerge (Bakhtin, 1999): “It’s a case of everyone still learning about it every day. Even professionals are still understanding” (Lauren).

Contrasting with other participants, Olivia demonstrated difficulty trusting her own ideas. Being offered perspectives by her team seemed to reinforce the idea that her own interpretations were invalid:

I know that sometimes my point of view is sometimes wrong and I'm looking at it from the wrong perspective because of my mental health issues. So, it's good and try and think about it from their point of view (Olivia)

2.3.2.2 *We're all just human beings*

Prior to entering mental health services, most participants recalled believing that there was something fundamentally “wrong” (Olivia) with them, a perspective which isolated them from their peers. For some, was this reinforced by diagnostic labels and perceived efforts by practitioners to “fix” (Edel) them. A common position within the narratives however was that their mental health difficulties were understandable given their context. This is illustrated by Mark in the following excerpt: “I don't think anyone can deal with it in its entirety like, it's, it's too much for one person to go through”. This quote conveys a sense of ‘common humanity’ that is central component of self-compassion (Neff, 2003).

Efforts to conceal and suppress distress were replaced by an understanding that to feel emotional pain is human, suggesting a movement away from shame. This motivated participants to improve communication with their support network and motivated the two parents in the study to pass this understanding onto their children:

We should teach our children that that's ok, and they don't need to think that it's weird for mama to cry or whatever. Dya know actually your parents and yourself are just human beings and we have emotions and sometimes we need to express those by crying. (Olivia)

Feeling connected to others was not an absolute process however, and a logical way of understanding did not necessarily lead to felt change. Olivia exemplifies the difficulty in integrating a rational awareness of one's humanity with a lingering felt sense of shame: “although I know better at this stage, it's hard not to feel that something is wrong with you”.

2.3.2.3 *Meaning through a relational and systemic lens*

Participants reflected on a movement away from seeing themselves as the source of the problem, toward relational and systemic accounts of their journey to mental health

services. Several participants acknowledged that mental health difficulties are transgenerational: “I’m sure she had plenty of mental health issues of her own. Which also she didn’t deal with and took out on us largely. Which is probably where all my mental health issues stem from originally” (Olivia). The loss of social relationships was also frequently stated, as was the impact this had on mental health and identity. Mark, for example, considered the loss of his relational identity as the turning point for his journey to mental health services:

Things you say and things you do, they’re characteristics of you, but when people don’t know you you can’t necessarily get away with that [...] things that used to make you tick are taken from you. (Mark)

Participants who brought their network to treatment meetings indicated an awareness of the transactional nature of difficulties. For some, such as Edel, this connected with culture: “There’s that thing ... the cultural thing of going ‘ah no ‘tis fine’ and him being like ‘no you really actually have to use your words and say ‘I’m not ok’”. Each of these narratives illustrates a movement away from self-blame, towards a normalisation of mental health in the context of complex relational systems.

2.4 Discussion

This phenomenological study offers a unique contribution to the study of meaning-making in mental health services, by documenting the experiences of individuals in an innovative OD-informed mental health service in Ireland. Several of these participants reflected on their prior involvement with non-dialogical services, offering further support to existing research on power imbalances and dehumanising experiences within non-dialogical mental health services (Bacha, Hanley, & Winter, 2019; Bracken, 2002; Guilfoyle, 2003; Russo & Sweeney, 2016; Stovell, Wearden,

Morrison, & Hutton, 2016; Tew, 2017). The findings in relation to the OD approach are suggestive of a different experience.

2.4.1 OD as a humanising and empowering approach

Current and former service users have repeatedly documented their desire to be trusted, listened to, and taken seriously by mental health professionals (e.g. Borg & Kristiansen, 2004; Laitila, Nummelin, Kortteisto, & Pitkänen, 2018; Stovell et al., 2016). They wish to move beyond the identity of a ‘patient’ and be “in the driver’s seat of one’s own life” (Tondora, Miller, Guy, & Lanteri, 2009, p. 2). The current findings provide support to the humanising potential of dialogic principles (Wilson, 2015). Participants felt that their voice was considered as equal to that of practitioners, and the transparency in the service led to the experience of that which Shotter (2006) terms ‘withness’. In dialogic practice, this concept positions practitioners as facilitators of conversation, rather than providers of expert knowledge. The aim is to challenge practices of talking ‘about’, whereby people can feel dehumanised and become the object, rather than subject, of meaning (Wilson, 2015). Transparency facilitated participants to safely explore their experiences without fear of judgement. Previous research has shown that a lack of transparency and a lack of feeling connected to practitioners can threaten meaning-making among service users and lead to a withholding of information (Ådnøy Eriksen, Arman, Davidson, Sundfør, & Karlsson, 2014; Ekeberg, 2011).

Being known by one’s team members, involved in treatment discussions, and asked about many areas of their life were noted as important factors in feeling treated like a human being, as opposed to a ‘case’. For several participants, this contributed to less restrictive interpretations of their mental health. These elements may be

considered by practitioners in the continuous improvement of services to align with the aims of the 'recovery' movement (Department of Health, 2006).

Participants expressed ownership over their narratives and trusted and acted upon their own ideas for recovery. It may be that these individuals already had clear ideas about their mental health, and the uniqueness of the OD informed service came from feeling safe to express and act on their own interpretations without fear of judgement from practitioners. Considered within a relational frame and drawing from literature on validation however, it may be that individuals learnt to trust their own voice, through validation by their team (Ådnøy Eriksen et al., 2014; Linehan, 1993).

The experience of trusting one's voice was robust, though not unanimous. One participant experienced difficulty, and at times felt invalidated by her team's ideas. Guilfoyle (2003) suggests that within a dialogic context, cultural expectations that professionals have the answers can lead service users to search for implicit signals as to the 'right' way of viewing a problem. Additionally, a history of invalidation can cause an entrenched distrust of one's own experiences (Linehan, 1993), which may pose a challenge to dialogical thinking among service users. As this participant was involved in this service for the least amount of time, it may be of benefit for future research to consider how self-trust and self-validation may change over time.

2.4.2 Professional versus personal meaning

Disagreements in meaning can cause a challenge to both professionals and service users. From a professional perspective, this can be interpreted as a lack of 'insight' and lead to concerns of risk in the empowerment of service users (Drake & Deegan, 2015). For clients however, it can be invalidating and disempowering when alternate meanings are imposed that challenge their own beliefs about their health (Colombo, Bendelow, Fulford, & Williams, 2003). Across narratives, there was an appreciation

of the multiplicity of valid perspectives. Rather than having to prove the validity of their own perspectives, or subscribe to the interpretations of their team, participants demonstrated an appreciation of the multiplicity of valid perspectives. At the same time, they felt free to disagree with their team and act on their own views of what might help their recovery. These findings are suggestive of the OD principles such as dialogism and polyphony (Olson, Seikkula, & Ziedonis, 2014), which aim to allow for complexity, uncertainty, and apparent contradictions in meaning.

The dominance of monological approaches among mental health professionals however may continue to pose challenges to the empowerment of service users in defining their own meaning (Gonçalves & Guilfoyle, 2006). Practitioners may wish to consider how their own assumptions may inhibit the voices of service users and consider how a dialogical perspective could allow for the existence of multiple truths.

2.4.3 Relational and compassionate understandings

Each narrative in this study reflected on a journey away from self-blame and isolation, towards a relational understanding of one's mental health that sees distress as a normal response to the context. This led to a sense of shared suffering and common humanity that is central to self-compassion, and a core theme among recovery narratives (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011).

One of the underlying principles of OD is emphasising stories, not symptoms (Olson, Seikkula & Ziedonis, 2014). Practitioners are trained to find the validity in clients' distress and problematic behaviour within a relational frame. It may be that the resulting dialogic conversations led to the emergence of these relational narratives over time. The cross-sectional design of this study precludes a definitive conclusion about cause and effect. Further studies may wish to incorporate a longitudinal design to explore meaning-making in OD over a trajectory of time.

These findings are consistent with the aims of the ‘recovery’ movement in prioritising collaborative relationships and personal meaning and may therefore inform service planning in clinical contexts. Among more recent efforts to prioritise an emphasis on meaning in mental health is the Power Threat Meaning (PTM) Framework (Johnstone & Boyle, 2018), published by the British Psychological Society’s Division of Clinical Psychology. This document provides a framework of understanding mental health difficulties that sees individual meaning and experiences of power and threat as central. The underlying assumptions are similar to that of OD, and there may be scope for practitioners to incorporate this framework into existing OD informed services.

2.4.4 Limitations and suggestions for future research

Outcome measures in research on OD to date have focused on mortality, need for psychiatric treatment, frequency and duration of hospitalisations, return to employment and rates of disability allowance (Bergström et al., 2018; Seikkula et al., 2006). A recent review of this evidence base however has identified a lack of methodological rigor in both qualitative and quantitative studies (Freeman, Tribe, Stott & Pilling, 2019). Thus, although initial findings are promising, no strong conclusions can be drawn about efficacy. The current research is not a study of efficacy, however it explores the construct of meaning-making, a central focus of the OD approach. In the context of the poor methodological quality of previous studies, the limitations of this research are of critical importance to consider.

Inherent in IPA is an inability to generalise, although there may be scope for theoretical transferability of the findings. The current study also cannot conclude as to the specific principles of the OD approach that resulted in the meaning-making processes evident. The cross-sectional design of this study precludes a definitive

conclusion about cause and effect. Further studies may wish to explore specific change processes in depth, in addition to using longitudinal designs to consider the process of meaning-making over time.

The service where this research takes place necessitates that service users receive payment for any involvement they have with the co-production of research. As no funding was available for the current research, service users were not involved in co-producing or reviewing themes. Such respondent validation can improve the credibility of findings and accuracy of the researchers' interpretations and this is therefore a significant limitation (Birt et al., 2016). Future research may benefit by including service users in this process and considering how they can be more fully integrated into the design and coproduction of the research.

2.4.5 Conclusion

This phenomenological study contributes to a growing body of research of innovative mental health services that challenge traditional ways of working. The participants provide evocative accounts of meaning-making within an OD informed mental health service, drawing from experiences of non-dialogical services to make valuable comparisons. Specifically, the narratives suggest OD as a humanising approach to services, which facilitates, rather than imposes meaning, and may lead to relational understandings of mental health that reduce self-blame. These findings are consistent with the aims of the 'recovery' movement, which prioritises collaborative relationships and personal meaning.

2.5 Acknowledgements

My deepest gratitude goes to the people who participated in this research by sharing their story.

2.6 References

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2.7 Chapter Two: Appendices

2.7.1 Appendix A: Journal of Mental Health Author Guidelines

The following guidelines were taken from: <https://www.tandfonline.com/loi/ijmh20>

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The *Journal of Mental Health* is an international forum for the latest research in the mental health field. Reaching over 65 countries, the journal reports on the best in evidence-based practice around the world and provides a channel of communication between the many disciplines involved in mental health research and practice. The journal encourages multi-disciplinary research and welcomes contributions that have involved the users of mental health services.

The international editorial team are committed to seeking out excellent work from a range of sources and theoretical perspectives. The journal not only reflects current good practice but also aims to influence policy by reporting on innovations that challenge traditional ways of working. We are committed to publishing high-quality, thought-provoking work that will have a direct impact on service provision and clinical practice.

The *Journal of Mental Health* features original research papers on important developments in the treatment and care in the field of mental health. Theoretical papers, reviews and commentaries are also accepted if they contribute substantially to current knowledge.

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Journal of Mental Health is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Journal of Mental Health accepts the following types of article: Original Article, Review Article, Research and Evaluation, Book Review, Web Review.

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Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

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Please include a word count for your paper.

The total word count for Review Articles should be no more than 6000 words. All other articles should be no more than a total of 4000 words. We do not include the

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Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

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3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. Between 3 and 8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
5. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
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For multiple agency grants
This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].
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At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

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2.7.2 Appendix B: Letter of Response to Ethics Application

04/12/2017

Dear Niamh,

Thank you for presenting your work to the D.Clin. Research Ethics committee and I am sorry for the rather tardy response.

Clearly, the work presented is still undergoing development and so we cannot offer approval at this stage. Hopefully, things will have greater clarity following your meeting with your supervisors. We look forward to seeing your revised submission as soon as possible. The next ethics meeting is in early February but we ask that you submit a proposal to us before this and we will endeavour to consider it before that meeting.

Issues arising from your earlier proposal may be relevant for your consideration and we provide the salient points below.

Good luck with your research.

Sean Hammond

Issues to consider:-

- First, remove reference to UCD on the invitation letter!
- You need a firm foundation before you can proceed. Please familiarize yourself with all the relevant literature and build up a sound knowledge base. This should be evident in the proposal background and justification for research.
- Consider the confidentiality issues – esp. transcription – can this not be done by you?
- Please consider the nature of the research and what potential benefit it may have and to whom.
- The letter of invitation appears quite cold, please and thank-yous go a long way in obtaining participant compliance.

- The research question is rather vague and there is no clear line up of the method with the question.
- More clarity on data storage and the limits of confidentiality.
- Ensure that staff are informing without advocating for the research as it is important to avoid any sense of coercion.

More specific issues to consider

- How will you operationalize 'Mental health'? Does this mean voice-hearing, mood, anxiety levels, delusions, hallucinations, etc. No operationalization is offered in the aims or brief description of the project.
- The study is designed to sample participant's understanding of mental health after just three face-to-face contacts with a care service. Given that the expectation is that open dialogue will produce some difference in interpretation of mental health, how have you estimated that 3 sessions will be a sufficient 'dose' to detect a difference?
- In terms of treatment fidelity, do we know whether any of the staff providing services through the Open Dialogue service also work in the treatment as usual service, as this is a potential confound (i.e. those staff are likely to integrate ideas and principles that they have seen working in OD to their work in routine practice).
- How will you ensure that the two groups are in any way comparable, to enable you to draw conclusions about the differences between the groups' 'subjective understanding of mental health' being due to the OD programme.
- Your exclusion criteria include 'Those presenting as actively psychotic, those at acute risk of self-harm or suicidal...'. Is there a risk, given the short time frame involved in participants having to have had only three sessions, that many of the participants will be excluded on this basis? What scoping work has been done to establish that these exclusion criteria will not exclude the majority of potential participants? Which also leaves the study open to criticism that the sample becomes very unrepresentative.
- What risks of bias are there in the appointed members of the mental health team choosing participants?
- Why is there an ellipsis in the first bullet point of the consent form?
- Wording of consent 'before you begin the study'? This does not seem to be the right phrasing for the participant.
- Bullet point 5 runs together the concepts of confidentiality and publication in a way that could be confusing for the participant.
- Given that the participants have been recently referred to a mental health service and have just begun assessment or / treatment, what procedures will be put in place to mitigate against any risk to disruption to their treatment that the interviews may cause.

2.7.3 Appendix C: Ethical Conditional Approval

15th March 2018

Dear Niamh,

Clinical Psychology Research and Ethics Committee**How do people participating in Open Dialogue make meaning of their mental health difficulties?**

Thank you for your resubmission. Based on your written proposal and further clarification and discussion during the meeting, the decision of the panel was:

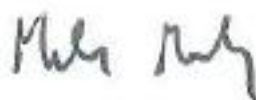
- **Pass, conditional on required revisions**

In formulating a revised submission please attend to the following issues raised by reviewers on the current proposal:

- Remove explanation mark from page 21
- Exclusion criteria, this should be reflected in the write-up
- Look at the literature on “meaning making” on other benchmarking studies
- Data storage – copy the audio files from the dicta phone to an encrypted laptop and then delete from dicta phone.

Every best wish with making these revisions.

Yours sincerely,



Dr Mike Murphy

Chair Clinical Psychology Research and Ethics Panel

Professor John McCarthy
Head of School of Applied Psychology

Ollscoil na hÉireann, Corcaigh
National University of Ireland, Cork

Appendix D: Ethics Amendment Letter13th February 2019

School of Applied Psychology UCC Ethics Committee

RE: “How do people participating in Open Dialogue make meaning of their mental health difficulties?”

Dear Ethics Committee,

I am writing to request an amendment to my previous ethics application for the study entitled “How do people participating in Open Dialogue make meaning of their mental health difficulties?”. The methodology initially chosen for this study was grounded theory, however further consideration of the focus of the study identified Interpretative Phenomenological Analysis (IPA) as a more pertinent fit. This change has no implications for participant recruitment or procedure which remain as already approved by SoAP Ethics committee.

I trust this is all in order. Please do advice if I need to take any further action.

Yours sincerely,

Niamh Doyle

Trainee Clinical Psychologist

2.7.4 Appendix E: Ethics Amendment Email Thread

Ethics amendment

Inbox



Niamh Doyle <116222795@umail.ucc.ie>

to Mike, Nora, Iseult, Maria

Dear Mike,

I hope you are keeping well.

Please see attached a letter to the ucc ethics committee requesting an amendment to my ethics application for my thesis.

All the best,

Niamh



Niamh Doyle <116222795@umail.ucc.ie>

to Mike, Nora, Iseult, Maria

Apologies - And here is the attachment.

Attachments area



Hennessy, Nora <NHennessy@ucc.ie>

to Mike, Maria, me, Iseult

Dear Niamh,

This has been approved.

Kind Regards,

Nora

Nora Hennessy | Programme Administrator, DCLIN Psychology| School of Applied Psychology| Distillery House, North Mall Campus |UCC ||Ph: (021) 490 4512/ 490 4552

2.7.5 Appendix F: Demographic Questionnaire

How do people participating in Open Dialogue make meaning of their mental health difficulties?

DIRECTIONS: Please answer each question by circling the correct answer or filling in the space provided.

1. What is your age? _____

2. What is your gender? _____

3. What medication are you currently taking, if any?

4. How many meetings have you had so far in Open Dialogue?

5. Please tick the services that you have turned to before for help with mental health difficulties, and how long or how many times you attended each.

Service	How long or how many times?
<i>e.g. Family doctor</i> GP ✓	<i>Twice</i>
<i>e.g. Counsellor</i> ✓	<i>Weekly for 2 years</i>
Family doctor/GP <input type="checkbox"/>	
Counsellor/therapist <input type="checkbox"/>	
Psychologist <input type="checkbox"/>	
Psychiatrist <input type="checkbox"/>	
Telephone Counselling service <input type="checkbox"/>	
Telephone helpline <input type="checkbox"/>	
Social worker <input type="checkbox"/>	

Hospital/A&E service <input type="checkbox"/>	
Chemist or pharmacist <input type="checkbox"/>	
Alternative or complementary practitioner <input type="checkbox"/>	
Peer support group <input type="checkbox"/>	
Other <input type="checkbox"/>	
Prefer not to say <input type="checkbox"/>	

6. Who do you see as part of your support network for your mental health recovery?

- a. Open Dialogue team ☐**
- b. Family ☐**
- c. Friends ☐**
- d. Work colleagues ☐**
- e. Voluntary agencies ☐**
- f. Community groups ☐**
- g. Family Doctor / GP ☐**
- h. Accident and emergency Department ☐**
- i. Other – please state**

2.7.6 Appendix G: Interview Protocol

How do people participating in Open Dialogue make meaning of their mental health difficulties?

Interview Protocol

This study aims to examine how people find meaning in their mental health difficulties through engagement in Open Dialogue. Data will be collected through semi-structured interviews. The researcher will follow Charmaz' (2006) guidelines for intensive interviewing to explore participants' understanding and experiences in depth. The time will be decided with the participants individually and will last approximately 60 minutes. The interviews will be conducted by the Trainee Clinical Psychologist (Niamh Doyle), Senior Clinical Psychologist (Dr Iseult Twamley), or Counselling Psychologist (Dr Maria Dempsey) on West Cork mental health services premises. Interviews will take place on a day that the Senior Clinical Psychologist (Dr. Iseult Twamley) is also on the premises and available if the participant experiences significant distress. A dictaphone will be used to voice record the interviews which will be subsequently transcribed by the Trainee Clinical Psychologist.

Each interview will have four sections: introduction, brief demographic questionnaire, interview and conclusion:

Part 1: Introduction

Participants will be welcomed and thanked for agreeing to take part in the study. The researcher will introduce herself in the context of being a Trainee Clinical Psychologist in University College Cork and her particular interest in this area of research. They will then be given a study information sheet and a consent form to read. The researcher will read the consent form aloud before inviting the participant to sign it.

Part 2: Brief Demographic Questionnaire

Participants will be asked to fill out a brief demographic questionnaire (see APPENDIX 1). The researcher will talk through each question. Participants will have the option of filling in the answers themselves or verbally answering and allowing the researcher to write in their verbal responses.

Part 3: Interview

In line with the recommendations of Glaser (1998) and Charmaz (2006), there will not be a static interview schedule. All interviews will begin with an opening question, inviting the participant to talk about how they came to the Open Dialogue clinic. Using the participants' own language, there will be a follow-up question about why this (e.g. mental health difficulty) is happening for them. The interviewer will attempt to follow the participants' lead, making a concerted effort to try to understand their point of view and actions (Charmaz, 2006). It is expected that the researcher will draw on the interview anchor points (see below), which will be refined as data is analysed on an on-going basis. The specific questions that make up the interview will depend on what the participants talk about in response to the opening questions. Examples of ending questions are also provided below.

Anchor Points

1. "Tell me about how you came to the Open Dialogue clinic"
2. "What difficulties/challenges are you looking for support with?"
3. "Do you have an understanding about how these difficulties [using the participants' language] have come about?"
4. "What has the experience been like trying to make sense of your mental health difficulties in Open Dialogue?"

5. “Have your team discussed with you how your difficulties might be understood?”

Ending Questions

1. “Is there anything that you might not have thought about before that occurred to you during this interview?”
2. “Is there anything else you think I should know to understand your mental health better?”
3. “Is there anything you would like to ask me?”
4. “What has it been like for you to talk about your understanding of your mental health issues in this way?”

Part 3: Conclusion

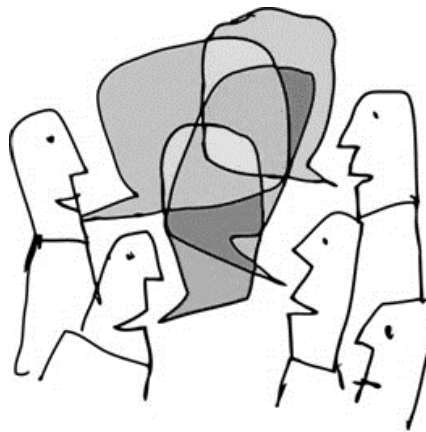
Following the interview, the researcher conducting the interview will thank the participants for their participation in the study and remind them that if they have any questions at a later date, that they can contact the researcher. The researcher will also ask how the participant is feeling and what the experience of the interview was like for them. If they have any unease or distress at the end of the interview process, they will be guided to seek support from Iseult Twamley, Senior Clinical Psychologist on their mental health team. If deemed necessary, an additional meeting with the participant and his/her mental health team will be rearranged within less than one week of the interview. They will be reminded that if, when reflecting on the interview, they have any questions or concerns they can contact the researcher or her supervisor.

2.7.7 Appendix H: Flyer

How do people participating in Open Dialogue make meaning of their mental health difficulties?

Are you currently in Open Dialogue?
Would you like to share your experience
with us?

We are trying to understand how people experience
Open Dialogue and make sense of their experiences



What will I have to do?

- One 1-hour interview in person
- We will ask you about your experience of Open Dialogue and how you understand your difficulties

Taking part or not taking part will in no way affect the mental health care you receive.

Interested?

- Contact Niamh Doyle at Niamh.Doyle5@hse.ie
- Or talk to Dr Iseult Twamley in the Open Dialogue clinic

2.7.8 Appendix I: Information Sheet

How do people participating in Open Dialogue make meaning of their mental health difficulties?

INFORMATION SHEET

Purpose of the study. The study is concerned with how people make sense of their mental health difficulties through Open Dialogue.

What will the study involve? The study will involve an interview that will last about 60 minutes where you will be asked questions about your experience of Open Dialogue so far and how you make sense of your mental health difficulties. The interviews will take place on West Cork Mental Health Services premises.

Are there any benefits to taking part? This study will give you the chance to talk about your own mental health and how you understand your difficulties. You will help us better understand others who come through Open Dialogue and how best to help them to make sense of their difficulties.

Are there any risks to taking part? Telling your personal story about mental health may be upsetting. You do not have to answer every question and can stop the interview or leave the study at any time, without giving a reason. If you experience any distress, support will be available from Dr Iseult Twamley, Senior Clinical Psychologist and your Open Dialogue Team.

Do you have to take part? You do not have to take part. If you decide not to take part, this will not affect your mental health care in any way.

Will your participation in the study be kept confidential? The interviews will be audio recorded, transcribed and then deleted. Your involvement with the study will remain confidential to the team. Your interview will be anonymised and no identifying information will be used. The study will be written up for a thesis for UCC and may be published in academic papers or presented at conferences. Any extracts that are quoted in the thesis or other reports will be entirely anonymous. Your name will be changed and any details of your

interview which may reveal your identity or the identity of people you speak about will be disguised.

If you inform the researcher that yourself, or someone else is at risk of harm, we may have to report this to the relevant authorities – we will discuss this with you first, however we may be required to report with or without your permission.

What will happen to the information which you give? The data will be kept confidential for the duration of the study, available only to me and my research supervisors. The brief demographic questionnaire and informed consent form you fill in with be locked in a filing cabinet in University College Cork. The transcribed interview will be securely stored on an encrypted password-protected computer. On completion of the project, the data will be retained for a further ten years and then destroyed. After completion of the interview should you wish to withdraw from the study you can do so up to two weeks post interview. In this case you will need to email me at Niamh.Doyle5@hse.ie or talk with Dr. Iseult Twamley to let us know. The transcript of your interview will be deleted and nothing that you said will be used.

What if there is a problem? At the end of the interview, I will discuss with you how you found the experience and how you are feeling. If you feel uneasy or distressed, you will be encouraged to contact Dr Iseult Twamley, Senior Clinical Psychologist in Open Dialogue and/or your Open Dialogue team. If you like, a meeting with your Open Dialogue team can also be arranged within one week of the interview.

Who has reviewed this study? Approval for this study was obtained by the School of Applied Psychology UCC ethics committee.

Any further questions? If you need any further information, you can contact me: Niamh Doyle at Niamh.Doyle5@hse.ie.

If you agree to take part in the study, you will be asked to sign the attached consent form.

2.7.9 Appendix J: Consent Form

How do people participating in Open Dialogue make meaning of their mental health difficulties?

INFORMED CONSENT FORM

We invite you to take part in a study looking at how people attending Open Dialogue make meaning of their mental health difficulties.

- The purpose and nature of the study has been explained to me in writing.
- I understand that I can withdraw permission to use data from my interview within two weeks after my interview, in which case the material will be deleted. I can do this by contacting Niamh Doyle on Niamh.Doyle5@hse.ie or Dr Iseult Twamley on 02752970.
- I understand that taking part involves an interview about my mental health difficulties.
- I understand that even if I agree to take part now, I can refuse to answer any question without any consequences of any kind.
- I agree to my interview being audio-recorded.
- I understand that in any report on the results of this research my identity will remain anonymous. This will be done by changing my name and disguising any details of my interview which may reveal my identity or the identity of people I speak about
- I understand that disguised extracts from my interview may be quoted in a dissertation, conference presentation or published paper.
- I understand that if I inform the researcher that myself or someone else is at risk of harm they may have to report this to the relevant authorities - they will discuss this with me first but may be required to report with or without my permission.

By signing below you are agreeing that you have read and understood the Participant Information Sheet and that you agree to take part in this research study.

Participant's Signature

Date

Printed name of person obtaining consent

2.7.10 Appendix K: Debrief Information Sheet

How do people participating in Open Dialogue make meaning of their mental health difficulties?

DEBRIEF INFORMATION

Thank you for participating in this study. Your participation today is greatly appreciated and will hopefully help mental health professionals better understand how individuals view their mental health.

As you know we are interviewing people attending the Open Dialogue mental health service in West Cork to examine how people make sense of their mental health difficulties.

Interviews are audio recorded and will be transcribed and then deleted. The information you shared will be treated with full anonymity. Your name will not appear on the transcripts and pseudonyms will be used for all other names you shared. If the study is published in a scholarly journal or presented locally and nationally, there will be no way of identifying your responses in the data archive. Your participation in this study will not affect your care in any way.

You can withdraw from the research within two weeks of completing the interview. In this case you will need to email me at Niamh.Doyle5@hse.ie or talk with Dr. Iseult Twamley (ph: 02752970) to let us know

If your participation has caused you concerns, anxiety, or any distress, we encourage you to call Dr Iseult Twamley at 02752970. Iseult is a Senior Clinical Psychologist with the Open Dialogue team and is available to give individual support to anyone who experienced distress. We will also be happy to arrange a meeting with you and your mental health team within one week from today.

The results of the study will be made available in the Open Dialogue clinic by summer of 2019. We would encourage you to read them and would be delighted to talk about them if you wanted.

Thank you again for your participation.

Yours sincerely,

Niamh Doyle

Trainee Clinical Psychologist

2.7.11 Appendix L: Sample of Analysed Excerpt from Lauren's Transcript

Interview Statement	Exploratory comments	Emerging Themes	Memos
	Descriptive comments		
	Conceptual comments		
	Linguistic comments		
I: Could you start by telling me how you came to Open Dialogue?	Diagnosed with Schizophrenia		
P6: Basically when I was a child I got diagnosed, well not I haven't been diagnosed, but I've got schizophrenia so I hear voices so when I was a child it progressed and stuff but I got referred because I tended to cut myself and I didn't want to tell my mum but I was like well I've got my brothers to think of and I've got my mum to think of so I said, my mum referred me to my GP, we were talking about it and he said, ok, as I was 17 I was too, I was in between CAMHS and like a proper counsellor or psychiatrist so he wasn't too sure if CAMHS would let me in or psychiatrists so he referred me to Open Dialogue to see how I would progress.	Progressing Schizophrenia	Lifelong MH	
I: and can you tell me when you say Schizophrenia, could you tell me what Schizophrenia means for you?	Cutting self	Identifying with diagnosis	
P6: Well it varies on the person but like for me, it was more of like a negative, like everything was on me. Like I have low self-confidence anyways, and the voices or you could say the demons sort of thing would constantly say like I'm not good enough, my family doesn't like me. Like everything was negative but it was always on me it wasn't on anyone else. So, no one else was harmed, like I wouldn't say to anyone, they say that you're this or whatever. It was mainly about	<i>I've got schizophrenia – seems to identify with diagnosis even without a formal diagnosis</i>	Reluctance to tell mum	
	Not wanting to tell mum. <u>Why was she reluctant to tell mum?</u>	Family as motivator to seek help/open up	
	<u>Shame?</u>		
	Thinking of family	Referred by parent	
	Referred to OD		
	Acknowledging individuality of experience of a diagnosis	Individuality of experience	
	Experiencing everything on me		
	Having low self-confidence	Shamed by voices/internal shame	
	<u>Demons: is this her word?</u>		
	<i>On me – indicating shame or guilt? Guilt/shame often indicated as a weight</i>		
	Put down by 'demons'	Shamed by voices	
	Told I'm not good enough	Harming self from voices	

me and about putting me down. So that's why I attempted to cut myself because they like encouraged me to, so I was kind of like peer pressured, but it wasn't peer. So um, yeah really.

I: And when you say demons is that your own word that you call them?

P6: Yeah cause of course like when I came here I said it was like me, so it was like my sub-conscious but it was very like demonic like, the voice was mine but very low and wasn't like, wasn't something that I was used to hearing.

I: and when did they start?

P6: Well they started when I was like, say like when I was born like when I started like. But when I was a child, I thought it was just the way life was I didn't know what it was, so I just carried on. And then I was about 14 or 15 but they got, I was about 12 and they got worse. And at that time, I was starting first year, and I had just finished 6th class. And I wasn't doing great as in like, socially, in primary school. So, I um, didn't have many friends so of course had that on my mind. And at the age of 12 I kept wanting to go asleep and not wake up. I just didn't want to suffer secondary school. So, about age 12 I realised that it, I tried to ignore it thinking it was normal, so I just thought it was normal until about 5th year.

I: And how did that change come about in 5th year?

Experiencing everything on me

Putting me down

Encouraged to cut by voices

Seeing voices as demonic sub-conscious

Hearing voices since birth
Thinking this is the way life is
Carrying on

Not doing great socially
Not having many friends
Not wanting to wake up
Not wanting to suffer
'of course,' – indicating that it was natural to be thinking about social difficulties – hint of self-compassion?

Ignoring it; thinking it was normal

Emotion regulation difficulties?

Unable to tolerate suffering?

Use of suppression?

Individual interpretation of experience

Interpreting voices as sub-conscious

Lifelong MH
Unquestioned acceptance of MH

Struggling socially

Wanting to die

Suppressing MH

It seems that she uses her own word 'demons' to describe her experience. This doesn't come from a psychological understanding – possibly a spiritual way of interpreting her experience. Wondering if this was accepted by her team?

This seems similar to other transcripts – where social aspects were important in the development of mental health. Feeling disconnected, isolated from others, struggling socially – common themes. Not sure if this is related to her mental health or not – perhaps both influencing each other – can't tell here.

P6: I found 5th year a struggle anyway. Through secondary school there was highs and lows, like first year was great second year was fine, third year was stressful with the exams and stuff. Fourth year, I did transition year that was fine. 5th year I found it so stressful with exams and then like I had teachers saying about college I've got, it was just very stressful and I got, at that time my mum and, there was like family issues so I had that to worry about as well so I had a lot on my plate so I ended up coming like depressed and also the voices as well but louder as well as I was going downhill.

I: and depressed for you, what does that mean?

P6: I just didn't wanna, I didn't wanna get out of bed, I didn't wanna do anything I didn't want to go to school like. In 5th year I kept saying to my mum do I really have to move on can I not just leave and just ignore it. And she said you're gonna have to progress in school, so you need to finish your education. So, I didn't want to, I didn't want to do anything, I didn't wanna go to school or speak to anyone. But of course, I had a mask on so in school people thought I was fine. So of course, deep down I didn't wanna do anything. I just wanted to be in a hole and not get out.

Struggling through 5th year
Having highs and lows in school

Finding school stressful

Worrying about family
Having a lot on my plate
Becoming Depressed
Going downhill

Linking stressors to MH

Downhill – use of spatial orientation to describe her MH – ‘down’ sometimes represents a loss of social status

Describing depression; not wanting to get out of bed
Repetition of ‘didn’t wanna’ – seems to me to convey panic and overwhelm

Wanting to ignore it
Being told to finish education
‘of course,’ again – seems like a compassionate phrase – as if it was only natural, she was experiencing this

Not wanting to do anything
Wearing a mask

What would happen if she showed people how she was feeling? Is this a reference to shame?

Experiencing highs and lows in school

Culmination of stressors

Linking depression to stressors

Wanting to avoid social contact

Concealing MH from others

Use of metaphor to describe MH

Similar to other participants, life challenges and social difficulties are central to her mental health story

Wondering did she fear rejection. She has spoken about feeling shamed by her voices and told she is worthless. Did her self-isolation result from a fear or rejection?

<p>I: So that was the turning point?</p> <p>P6: Yeah. I mean I knew things weren't right anyway because of the family issues as well as school, I knew that that was putting on top of me so I knew that I had so much weight on my shoulders that I couldn't like, get it off me.</p>	<p><i>'In a hole' – use of metaphor – seems dark and isolated –</i> <u>Is she hiding from others or from herself?</u></p> <p>Knowing things aren't right <i>Weight – common expression of guilt or stress</i> Having weight on my shoulders <u>Is she linking MH to life stress?</u></p>	<p>MH as an embodied weight</p>	<p>The fact that she is referring to the 'weight' on her shoulders and the blame she refers to later on in her narrative may indicate that this weight refers to a sense of guilt or shame? Alternatively, could indicate the felt sense of pressure and stress</p>
<p>I: So, you remember them your whole life and they were normal to you.</p> <p>P6: Yeah, I didn't know it was any different.</p> <p>I: And would your family have been aware of them?</p> <p>P6: No one was really aware when I was a child because like, I didn't show it because I thought it was normal I didn't do anything about it, I didn't tell someone, I thought it's fine I'll just carry on as it is. And in primary school I had like, it was fine until about 5th class until I lost my best friend and, well not as in like a passing, but she went off to the other girls and course, I'm not a sporty person so, my primary school was very sporty whereas I'd be like, kind of like hiding in the shadows not wanting to do anything. So, I just thought it was normal I just thought it was part of me, so I didn't think anything of it. Of course, like the mask I had no one else knew. Well my family knew that something wasn't right because I'd try and do other, well like I'd try make sure my brothers and other people were ok, but I wouldn't put myself first so...</p>	<p>Unquestioned acceptance Not showing it as a child Thinking it was normal Not doing anything about it <u>She thinks it's normal, but it also seems like she is hiding it – perhaps she has some awareness that it is not normal?</u> Losing my best friend <u>This discussion of not being sporty seems sort of out of the blue – taken together with her holding a mask, perhaps she is indicating an awareness that she was already different from others and didn't want to further isolate herself.</u> Being different to my school</p>	<p>Unquestioned acceptance</p> <p>Assuming MH are normal</p> <p>Loss of social connection important to MH</p> <p>Identifying as different from social group</p> <p>Assuming difficulties are normal</p> <p>Wearing a mask</p> <p>Putting family first</p>	<p>So interesting to me that her voices were considered normal – because they were normal to her. Reminds me of the impact that a diagnosis can have on people – it takes their inner experience and turns it into a label that differentiates them from others.</p> <p>That her voices were 'part of her' – was that ok for her? Did she accept this? Or experiencing internal shame? Does she now</p>

	<p>Hiding in the shadows</p> <p><u>Has she now separated herself from her MH? Sounds like she previously assumed her MH was a part of her – but now things have changed?</u></p> <p>No-one seeing through the mask</p> <p>Family knowing something wasn't right</p> <p>Not putting myself first</p>		separate her MH as something distinct?
I: And was it your mother asked you to go to the GP?			
P6: Yeah because I attempted to cut myself and um luckily there was no scars or anything, but I attempted. And then the next day um, I went up to my mum and I didn't want to, I kept saying myself you know you can't do this; you don't want to worry your mum. But also, I was like, I have to because like I have 3 brothers and two of them are very young so about 6 and 5. So of course I think one of them was about 3. So of course, it would be very confusing for them. So, we have cats and a dog, and I couldn't really say oh it was a cat, because cats give multiple scratches whereas it was just one. So, I had to tell my mum even though I didn't want to. So, then she rang up my GP and said can we have an appointment and of course then I had to tell him about it so I got referred here.	<p>Attending GP because of cutting</p> <p>Not wanting to worry mum</p> <p>Considering family</p> <p>Considering how siblings would understand cutting</p> <p>Telling mum reluctantly</p> <p>Having to tell GP</p>	<p>Reluctance to ask for help</p> <p>Family as motivators for help-seeking</p> <p>Disclosing MH to mum</p>	
I: Do you remember that first appointment with your GP?			
P6: Yeah, I was very like, nervous about telling him because I didn't want to be judged, I didn't wanna be put on tablets as soon as. I didn't wanna be say locked up in a mental place because of what I did. So, I was	<p>Fear of judgement from services</p> <p><u>Awareness of stigma</u></p> <p>Fear of being disconnected from society</p>	<p>Fear of judgement from services (external shame?)</p>	<p>Highlighting to the interviewer how scared and vulnerable she was. Taken with her narrative as</p>

very scared I felt very vulnerable. Because I was telling in a way, he wasn't a stranger, but someone non-family that I just attempted to cut myself, so I was very scared

She already felt fearful of her peers, now attendance at services poses further threat to her connections to her community
Vulnerable – this also feels compassionate to me – reflecting on the vulnerability of her position. Perhaps this also indicates the lack of power she had in services
 Not wanting to be put on tablets
Because of what I did: what did she do? Why
 Feeling scared and vulnerable
 Telling non-family

Vulnerability/powerlessness attending services

a whole, particularly her dissatisfaction

I: and was your mum in with you for that appointment.

P6: Yeah

I: And do you remember what you did say to the GP in that session?

P6: I just said, I didn't want to tell him but I attempted to cut myself and I explained that like, I said I think I have like I keep hearing, I got told that I should do it, it would go away if I did, and of course they didn't go away so, and he said ok, he said to me he said he'll try and send a letter to CAMHS as well as a psychiatrist around here but it took a while. So, he referred me here quickly and he wasn't too sure whether they would allow such a young girl in that isn't like an adult yet.

I: And would your GP have used the term Schizophrenia at the time?

Telling GP about cutting
 Telling GP about commanding voices
 Being told I should cut

Reluctantly telling services

Being referred by GP

GP mentioning Schizophrenia

P6: Not at the time no because that wasn't, he wasn't sure. He mentioned it but he wasn't quite sure. Um, and then when I came here, and it started to progress I started talking more about them. And that's when it roughly got diagnosed as Schizophrenia.

I: By Open Dialogue?

P6: Yeah so, they told my GP that we reckon it's Schizophrenia. So, they told him so he would know as well as myself.

I: And what was that like, did that fit for you?

P6: Em, it kind of pieced the puzzle together. Looking back, I did realise but, I didn't want to be known as the Schizophrenia girl like I didn't wanna go telling anyone. I didn't tell any of my friends because I was so scared of them knowing and I didn't wanna be judged. I didn't wanna be known as crazy. I didn't wanna tell anyone, but my family were understanding you know they were there for me, so I had, like I told a few close family members and they were ok with it. They were just making sure I was ok, but they still knew me as me so, at least I wasn't known as so and so's niece with Schizophrenia I was just known as the niece, or the cousin or the sister you know so.

I: And that fear about other people seeing you as the Schizophrenic - do you know where that fear came

Talking more about voices in OD
Being diagnosed with Schizophrenia

OD reckoning it was Schizophrenia

Schizophrenia piecing together the puzzle

Not wanting to be 'Schizophrenia girl'
Wanting to hide diagnosis
Feeling scared of being judged
Does she have an awareness that people with Schizophrenia can be known as crazy? Is she aware of this from others' experiences?
Not wanting to be known as crazy
Having an understanding family
Relief?
Family knowing me as me

Diagnosed

Diagnosis shared between services

Diagnosis piecing puzzle together

Diagnosis as a threat to social connections

Hiding – fear of judgement

Fear of MH becoming identity

Family seeing me as 'me'

Seems like a triple attack of fear. Firstly, fear of judgement for the 'family issues', then fear of judgement from services, then fear of judgement as a result of a diagnosis. Even though the diagnosis offered relief, it also posed a threat to her connections with her community

When she braved telling her family about her voices/cutting, she received a positive response. They did not judge her negatively or stigmatise her. I wonder what the impact of this was on her sense of self. Did it reduce some internal shame?

from? Would you have heard things about Schizophrenia before?

P6: Em I didn't really know anything about it. I think it was more, of course these days it's very much like, looking at social media looking at that sort of thing I kind of got scared. I didn't care about being judged like, but I didn't want to be judged. But it wasn't really anything, like I'd probably heard of Schizophrenia but I didn't know what it was, so I didn't look it up or anything. And I was scared because I saw social media I saw, you could say people who were footballers, or I heard like someone had depression and everyone knew that that person had depression and I didn't want to be known as like someone who had something completely different. Especially being in a small town, I didn't want anyone to know, like she's crazy she's got Schizophrenia she'll turn on you or something. So that was kind of like scary as well.

I: and do you think the diagnosis changed how you saw yourself at all?

P6: Not really no because of course like when I was putting the puzzle together realising I had it as a child I just thought well I am still me you know I've got this and I've got this but it's not going to change who I am you know. I was hoping that like they would mellow or like I can't really say that they stopped because they still are there, but I kind of was like this is how I am, I'm not going to call myself with the mental illness or

Not knowing anything about Schizophrenia

Feeling scared by social media
This contradiction; not wanting to be judged but not caring about being judged – I wonder does this signal high external shame but low internal shame?

Not wanting to be judged

Not knowing what

Schizophrenia is

Wanting to be accepted;

wanting to be 'normal'

Diagnosis identifies a person as 'different'

Not wanting to be known as different

Fearing small town would label me as crazy

Awareness of stigma

Feeling scared

Putting the puzzle together

Still being me

Not being changed by diagnosis

Hoping voices would mellow

Strength of own voice

Not calling myself crazy girl with mental illness

Seems confident in herself

Influence of social media on meaning-making of MH

Ambivalence about judgement about MH

Diagnosis as isolating

Fearing judgement

'still me' in context of diagnosis (refusal to internalise shame?)

Refusing to self-stigmatise
Using humour to cope

Appears that she did not judge herself growing up; she saw her difficulties as "normal" and so no reason to ask for help. This may signal low internalised shame for her difficulties. However, when she realised that her experiences were different from the norm, it raised high externalised shame and fear of stigma and rejection

the crazy girl. Like I do make fun and say like I'm crazy but that's just you know, take things on.

Confidence in her sense of self
– is this new? Or has this
always been present?
Making fun of being crazy

from others. However, it appears that she did not internalise this shame – she continued to hold on to her identity and refused to use her difficulties as her primary identifier. I'm wondering why she was able to not internalise shame. Did this help by the response she received from her family and/or services? Or did she recognise stigma of MH as a wider societal issue? Possibly helped by the lack of stigma from her mother as well as involvement in non-stigmatising services from a young age
My questioning here is putting my own words on it ('identity') – possibly too leading

I: So, you were able to keep your own identity as well.
P6: Yeah it didn't change who I was as a person it didn't change I dunno my style or anything else I still carried on but...

Diagnosis not changing who I am
'My style' – recognising other
attributes that she has that links
her to her peers. The diagnosis
did not invade all aspects of
herself. Perhaps indicates an
integration of her MH into her
identity

'Still me' in context of diagnosis

I: And what was your first meeting with Open Dialogue like?

P6: When I got, of course like being 17 as well as, I was very scared and of course going in here and it

Being scared of attending OD

Uncertainty about services

Really missed an opportunity here to dig deeper

being said like you're not going to go to a psychiatrist you're going to go to this. I didn't know what to look for, I didn't know what was going to happen. So, when I arrived, I was like, mum was there with me thankfully I was like, what if they judge me, what if they think that you know they can't help me. What happens if I don't get any help or if they judge me badly and they could say around [name of town] that this is the girl that got, is very crazy, stay away from her. But of course, luckily that didn't happen. and of course, afterwards after the session I felt relieved, I felt like a bit of weight was lifted off my shoulders I actually knew that they could sort of help me.

I: And was it much different from the meeting with the GP? What were the differences?

P6: It was very different because they didn't just ask about my mental health, they asked about school, they asked about my past, they asked about the family issues as well as like, they asked about anything. Like I liked it as well because it wasn't just on me. Like mum got an input, she got to say what she was feeling, I got to understand what she was feeling. I got to listen to what she had to say as well as what they had to say as well as what I had to say. So, we all got an input we all got to talk about it. Whereas with like a psychiatrist or the one I went to for that one day or my GP, it was quite like a box tick thing. Like they only ask specific

Not knowing what would happen

Fearing judgement
Fearing no help
Comfort in mother's presence
Fear of social connection
Fearing reaction of my town
Feeling relieved
Awareness of stigma of MH
Feeling a weight lifted
Knowing OD could help me
Of course – maybe this indicates a full trust in her team now? She knows now that of course her team wouldn't judge her
Hope

Comparing GP with OD experience; not being asked exclusively about mental health.
“not just on me” What does this mean? Did this signal that her team did not blame her for her MH? That MH has to be understood within a relational context?
Liking the opportunity to hear what mom and OD team had to say

Safety in mum's presence

Fearing social implications of attending OD

Relief in context of no judgement

Hope as a lifted weight

Attending to the many parts of me

Network involvement as not blaming

GP as 'box tick'
Asked only about illness

Not feeling judged in OD

I wonder did the network approach indicate to participants that their MH was being viewed within a wider context. Their MH wasn't something that could be understood only through taking an individual perspective – there was a relational context

questions about the illness and they didn't ask about anything else. And I didn't feel judged.

I: And were there a few people in the room from your team?

P6: There were like two people from the Open Dialogue team and then me and my mum. So, it was nice to have two different inputs as well as family members as well as my own. So, it was good to have their input, their ideas or what they thought it was or what they thought about it. So, it was nice to sit there and listen while they spoke amongst each other, so it was really good.

GP as impersonal

Each having an input
Describing GP and psychiatrist
intake as box ticking
Solely asking about illness

Liking different inputs

Hearing numerous ideas
Enjoying hearing OD discussion

and her MH was related to her
environment and experience.
Network approach also seems
to have taken away from some
blame

Experiencing network input

2.7.12 Appendix M: Quotes and emerging themes related to subthemes

Superordinate Theme: The Context of Meaning-Making: Relationships and Conversations		
Subthemes	Emergent Themes	Sample of Quotes
Treated as a person not a case	<p>Treated as a case, not a person</p> <p>Wider breadth of questioning</p> <p>Stigmatised identity in services</p> <p>Robotic interactions</p> <p>Reduced identities in services</p> <p>Real relationships with team</p> <p>Attention to the many parts of me</p>	<p>I didn't want to be known as the Schizophrenia girl like I didn't wanna go telling anyone. I didn't tell any of my friends because I was so scared of them knowing and I didn't wanna be judged. I didn't wanna be known as crazy. (Lauren)</p> <p>All of sudden I've become a number you know a statistic. Everything I say is like, you go through your reference book and you say like, social anxiety therefore these are the issues with this person. [...] Because Kelly and Patricia know my story from back to front like so its eh, I feel like I'm actually, or that they're talking about an actual person as opposed to a case. (Mark)</p> <p>I feel like this is like another family because of course the people who I talk to um, they, now it's more of a catch up we don't really discuss much. It's just a catch up you know it's nice that when you're here you're not judged. You can come, like if someone came here and didn't know what was going on they asked me, I'd be like you know its such a great service, you're, it's not robotic. (Lauren)</p> <p>I suppose my first experiences with it were just that of just the generic space to talk, I never really put a label on it, like Open Dialogue was what the girls used, but for me it was just Katie and Annmarie, I'm going to see Kelly and Aoife and everything. (Mark)</p> <p>So like that Kelly and Aoife will both come up and if [partner] is there we'll sit down and have a cup of tea and a chat like (Mark)</p>

		<p>I'd be passing on recipes to AnnMarie I do be making Butternut squash soup and I give her recipes for that. And porridge bread (Anna)</p> <p>I kind of bonded with them, I know Annmarie here for three years (Anna)</p> <p>And then you kind of just, it's as if you're talking to a friend but a friend that knows a lot. (Amy)</p> <p>It was very different because they didn't just ask about my mental health, they asked about school, they asked about my past, they asked about the family issues as well as like, they asked about anything (Lauren).</p> <p>You don't have certain questions you know like with a psychiatrist they say, how are you feeling? What's going on today? Has anything changed? And then that's it. And then here, you get different questions, like we spoke about school, we spoke about college, we spoke about the future and the voices. (Lauren)</p> <p>Whereas you know if you're in counselling well how have you been, how do you feel, what do you think about that? No, they ask you what you would like to talk about. And at the start, if you say I don't know, and they say, well how's your crafts, or did you see fuckface in the street or, dya know and. (Amy)</p> <p>I think it's that there's very much a feeling of like you could go to Open Dialogue about absolutely anything. You know so it doesn't mean, you know like if somebody goes, God I have to see a psychiatrist there is a thing of like fuck something major must have happened but it's like, yeah Open Dialogue it doesn't have to be like severe cases. (Edel)</p> <p>And sometimes what happens is when you go into a new space em and you kind of go, like I was raped by my dad. And when you kind of go and just say that at the start, people get like, em you know, very side tracked by it. To the point you're like well you're actually not valuing me and what else. And you're like yes I have, can I talk about what I'm feeling. So in that way it can be a bit demeaning. But like I've</p>
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		<p>never felt like that with the Open Dialogue with the two main people I'm with. They're usually like ok you're here today to talk about what happened last week or how your, cause it's very much the patterns I've been going through. (Edel)</p> <p>If you're in a counselor, you kind of, it's kind of known that there is something really really wrong with you. If you're in Open Dialogue you could just be having a bad week (Amy)</p> <p>Where a one on one counsellor wouldn't even give two craps about pictures of a little reindeer head you're after sewing. They wouldn't care. Where here they care. (Amy)</p> <p>At least it's not someone talking about you behind a door you know that kind of way. Dya know you're in the room and they're discussing you. (Anna)</p>
My voice is valued and equal	<p>Feeling listened to</p> <p>Feeling valued</p> <p>'Withness' vs 'aboutness' discussions</p> <p>Transparency</p> <p>Encouraged to contribute</p> <p>Accepted as I am</p> <p>Feeling safe to explore</p>	<p>At least it's not someone talking about you behind a door you know that kind of way. Dya know you're in the room and they're discussing you. (Anna)</p> <p>They could be writing down 'psycho' on the one on ones, whereas they're saying what would <i>you</i> say? (Amy)</p> <p>They have a reflection - I think it's called a reflection - and they kind of say, I feel, even though [participant's name] is upset, I think it's because of... or I wonder how [name] felt about what happened last week or, and dya know? And when they're doing that you're kind of going, they are listening to me. Dya know? Cause in a counsellor they just ask you how you doing, oh that's terrible and you're not getting...even though some people might say they're repeating it back to you that must be annoying, you know they're listening to you. And even though they're saying it in their own words they are actually listening and they're putting their own questions to each other and then they turn around and you answer them if you want. (Amy)</p>

		<p>There's no kind of 'look no, if you really wanted to get better you would've jumped at the chance'. So there's none of that kind of pressure to be a certain way (Edel)</p> <p>And sometimes it's good as in, if they say something if they're kind of going yeah this is what I think [Participant's name] means and I can turn around and actually go actually I didn't express some part of that very well I actually meant dadadadada. You know and they're like ohh ok. So it can be good that way. (Edel)</p> <p>It was very difficult because when I first went in, they said what do you want to talk about today and of course I didn't know what to talk about - should I talk about my voices or should I talk about everything or? Or that I'm so terrified right now and I don't want to be here. So it did, but of course they slowly eased me in. (Lauren)</p> <p>The recent one they said is there anything you want to talk about and I said 'just a general catch-up really' and they did ask questions about the voices and how are other stuff going, but you know I just, I just wanted a recap today. So it was good that I got to choose. (Lauren)</p> <p>I just enjoy being able to talk and have someone to listen (Mark)</p> <p>Sometimes I literally just wanna be like you just don't understand you don't seem to get it. But I think they do get it, they're just, they're being positive about it they're like oh no well you've still got this person that person the other person and I'm like, it doesn't feel that way (Olivia)</p>
Offered multiple Perspectives	Experiencing polyphony Many ways to view a problem	<p>With a one on one counsellor they can get very fixated on what they think or they might have certain beliefs and look at things in a certain way and it's good that they have a contradicting opinions sometimes em, because the more points of view you have the better. There's countless numbers of ways to look at most situations. (Olivia)</p>

	<p>Experiencing contrasting perspectives 'Answers' not provided</p>	<p>He's looking at it from a completely outside perspective of just what I look like to a normal person that's going to be really interesting to hear. (Olivia)</p> <p>Like I liked it as well because it wasn't just on me. Like mum got an input, she got to say what she was feeling, I got to understand what she was feeling. I got to listen to what she had to say as well as what they had to say as well as what I had to say. So we all got an input we all got to talk about it. (Lauren)</p> <p>I kept blaming myself that I was harming my family but you know, they ended up saying to me no (Lauren)</p> <p>So it's things like that they'd still have different opinions about which is really interesting as well because sometimes it's nearly like the you know the two angels on your shoulder and so it is interesting when things like that happen. (Edel)</p> <p>They don't always agree. Dya know. One doesn't say this is blue and the other says yeah it's blue. They say, no it's not, it's this way. Like Aifric she's a former nurse so she is a nurse, so she'd know more about medication than Kelly would so if Kelly was saying something like well that's a lot of medication Aifric, Aifric says no that's not. You know like, she'd know medically. (Amy)</p> <p>I'm not saying they share their personal details, but they say like, I've been through a similar situation of being scared of someone, or dya know. And it makes it more cosy. That it's not just you with a stranger that, the only thing you know about them is their name and that they can talk (Amy)</p> <p>And they think of different questions to put to you. And the fact that you can listen to what they're thinking, it kind of makes you think differently. (Amy)</p> <p>And sometimes as well its just kind of like em, they might share yeah I heard that on the news and that was my reaction, I can see why you would find that very tough. So that's quite cool. (Edel)</p>
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Superordinate Theme: Creating New Meanings		
Subthemes	Emerging Themes	Excerpts
Relational & Systemic Meanings	Disowning father Being a terrified child Scared of father Being a terrified child Helplessness Contrasting her parenting with her mother's 'bad' parenting Linking trauma to MH Linking personality to MH Suffering invalidated by mother Identifying unmet need for mother's help Recognising depression in hindsight	<p>This was pointed out through em, Open Dialogue you know. Like and it's quite blatant when you realise that everything you witness as a child is how you act later on in life. (Mark)</p> <p>I never heard her talking about anything before and then, so as I say like you know she was just a very happy person as far as I could see and then like that fast forward however many years you know and the situation where sadness is in my life and I don't know how to deal with it like (Mark)</p> <p>And then again like this is a way of main thing the Open Dialogue is is, that I don't want that situation to be the case for my kids. I don't want them in 29 30 years to turn around and say you know dad never showed me how to talk to mom like. So that's eh, that's the big thing for me is just rectifying it for their sake. (Mark)</p> <p>My mother showed any sadness or anything like that so I never learned how to do it. So in my relationship with [my partner] now it's the same in that I don't know how to do it. I don't know how to be sad and I don't know how to talk to her. (Mark)</p> <p>So, like it was very difficult for me to em, to carry on being the way I was. So, I was trying to find who I was then, and as I say I never really settled. Even now and I'm down here you know nearly 16 years and I still don't feel as though I'm part of the area like. (Mark)</p> <p>I don't want that situation to be the case for my kids. I don't want them in 29, 30 years to turn around and say 'you know dad never showed me how to talk to mom (Mark)</p>

	<p>Mother not meeting needs after 'interference'</p> <p>Parenting as responsibility to address MH</p>	<p>Cause your whole support network, your friends, everything you know is taken from you and you've to start again. (Mark)</p> <p>My mom left when I was six months old and my dad brought me up. So the fear of rejection kind of follows you (Anna)</p> <p>I'd a traumatic even I won't discuss here, in my childhood that kind of...made me a bit afraid through my life. (Anna)</p> <p>Interviewer: Do you know why you have such a strong sense that it's my fault? that there's something wrong with you? Participant: Again, probably going back to my childhood and my mother. And um, I'm sure I heard the phrase before 'what is wrong with you?' (Olivia)</p> <p>Yeah so we weren't really taught how to express or deal with our own emotions em because she never did and she never showed us how to so then, your emotions if you don't deal with them they just get bottled up and pent up and they build up and build up and then explode as a huge everything at once dya know which is not healthy (Olivia)</p> <p>Em that's why I'm working so hard to fix mine. So I don't pass them on to my son you know? Because he doesn't deserve that (Olivia)</p> <p>Which is you know, thinking back really should have been like 'are you ok?'. (Olivia)</p> <p>As far as I'm concerned she doesn't have the right to call herself my mother, cause parents don't treat their children that way. (Olivia)</p> <p>I want to teach him right I wanna show him that the world is, its ok dya know? I don't want to get him all fucked up he doesn't deserve that. He's like an innocent little boy I can't do that to him. (Olivia)</p>
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We're all just human beings	<p>Shared suffering</p> <p>Common humanity</p> <p>MH as 'normal'</p> <p>Recognising unmet needs</p> <p>Self-compassion</p>	<p>It was a perfectly normal thing I was going through, it just wasn't dealt with properly (Olivia)</p> <p>We should teach our children that that's ok, and they don't need to think that it's weird for mama to cry or whatever dya know actually your parents and yourself are just human beings and we have emotions and sometimes we need to express those by crying (Olivia)</p> <p>It's like, it's like as simple as someone being very good at math, and someone else being very artistic. Some people deal well with stress, others do not (Olivia)</p> <p>Although I know better at this point, it's hard to not feel like there's something wrong with you [...] you can't get that out of your head, it's drilled in there (Olivia)</p>

		<p>I think that's the main thing with people that have been abused. You do question yourself for a lot of years (Amy)</p> <p>I am still me you know, I've got this and I've got this but it's not going to change who I am (Lauren)</p> <p>I know I could get a bunch of people from [town] and gather them round and discuss it and say you know this is something that needs to be addressed. That mental health is a huge issue and that noone speaks about it no more (Lauren)</p> <p>I know that a lot of the reasons I have depression and a lot of reasons I you know have post traumatic stress disorder is because of what happened. But that's not like, life happens to everybody as well. So dya know what's kind of like, you know like anyone's gone through trauma. (Edel)</p> <p>Everyone's going like oh my god that's a huge trauma you've lost your house or whatever. But then its the day you stub your toe and somebody shouts at you at the supermarket may be the day that you're like you're like I don't know! Dya know what I mean its amazing what trips us up. (Edel)</p> <p>It's too much for anyone to go through (Mark)</p> <p>Number one is to, to paint a better picture of life for the children so they know, so they know it's ok to be unhappy and it's ok to be sad and you know, show them that mammy and daddy talk and...That's that's very important to me. (Mark)</p> <p>As I said I think that's the key to unlocking it is is, is conversing like. You know if I only had, like I say if I had my mother around I'd have that person to talk to. But reality is it should be [partner] because I want my little people to know that it's ok to be sad, and it's ok to worry (Mark)</p>
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		Mental health is the thing that's not really being talked about. You know you're shunned or that one is kind of mad or you know like kind of phrases that you don't, that we don't want to hear when we're suffering ourselves like you know. (Anna)
Trusting your own voice	<p>With openness comes confidence</p> <p>Encouraged to speak</p> <p>Treated like expert</p> <p>Having an input vs not</p> <p>Choosing content of sessions</p> <p>Removing 'expert' professional role</p> <p>Taking ownership over recovery</p> <p>Taking ownership over using OD</p> <p>Recognising uniqueness of individual experience</p> <p>Not needing answers</p> <p>Identifying own needs</p>	<p>It's not necessarily a place that I can seek answers from or anything like that. I just enjoy being able to talk and have someone to listen is I find the most helpful for me. Em, as I say I imagine every single person who comes through this door uses it differently. (Mark)</p> <p>I don't think there's a right or a wrong answer for everybody (Mark)</p> <p>It's not necessarily a place that I can seek answers from or anything like that. I just enjoy being able to talk and have someone to listen is I find the most helpful for me. Em, as I say I imagine every single person who comes through this door uses it differently. (Mark)</p> <p>I think a lot of my own, if not all my own mental health issues could be sorted by just talking to [my partner] like. You know which is why she comes; as a way to try and start conversations (Mark)</p> <p>All I'd say is my story is my story and how I have used this space has been the way that I use the space. You know the way that I do it mightn't work for anyone else like (Mark)</p> <p>They couldn't really say this is what it is and we can get rid of it for you [...] the more I spoke about it the more I understood what was going on that I knew that in that way I could help myself (Lauren)</p> <p>You know it's a case of everyone still learning about it every day. Even professionals are still understanding that there's like another one, or there's something new about this sort of one. So with hearing voices, everyone has it so differently (Lauren)</p>

	<p>Being genuine vs being what services want</p> <p>Owning own meaning</p>	<p>Like um the recent one they said is there anything you want to talk about and I said 'just a general catch-up really' and they did ask questions about the voices and how are other stuff going, but you know I just, I just wanted a recap today. (Lauren)</p> <p>I think the approach of less drugs and more talking is a better approach. That's my own opinion. (Anna)</p> <p>Some psychologists or psychiatrists can be very like, 'how we're gonna fix you', and it doesn't feel that way. It's like no, cause I'm at the stage that I know this is something I'm going to be living with (Edel)</p> <p>And she was kind of going oh but you know you're very sensitive. And I was like yeah I know, but it can be a bit of both. (Edel)</p> <p>It was very like this is how we're going to get rid of your depression and then, when I went into the group and I was like 'no this isn't how it's gonna work for me'. (Edel)</p> <p>Here they didn't even say 'oh God she's still in your bed'. It was, why is she still in your bed? And I was saying because I am still a little bit scared of fuckface and you know. And eventually I kind of just came in here before Christmas and I thought, I'm strong now I'm not 100%, and I'll never been 100% but I am strong. And so I moved out to my room. And when I came in the next time and I said it, it was like, oh my God well done you did it! (Amy)</p> <p>Well maybe they have a point maybe I should be looking at this differently. Maybe I need to make more of an effort to just kind of snap out of this and see the positive and just try harder (Olivia)</p> <p>I'm constantly coming up with new theories that all seem to make sense about why I am why I am but then, there's so many different ones, that it's like, I tend to instantly dismiss them and be like oh that's just me being you know, how would I come up with that myself I'm just being stupid. You know? Kind of, dismissive of my own theories. (Olivia)</p>
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2.7.13 Appendix N: Sample Extended Theme

Treated as a person, not a case

There was a dominant theme among participants that they felt humanised by the OD informed approach, in contrast to some dehumanising experiences in non-dialogical services. This theme was created by comparing and contrasting emerging themes across narratives such as ‘treated as a case, not a person’, ‘wider breadth of questioning’, ‘stigmatised identity in services’, ‘robotic interactions’, ‘reduced identities’, ‘real relationships with team’ and ‘attention to the many parts of me’. Within a relational and dialogical approach, meaning-making is understood to emerge through dialogic conversation and collaborative relationships (Anderson, 2012). Thus, to understand how individuals make sense of their mental health, it is pertinent to consider the conversations and nature of the relationships between participants and their OD informed team.

Non-dialogical services. In some non-dialogical services, individuals felt reduced to numbers and categories, without the agency to contribute to discussions on diagnoses. They linked this to “robotic” (Lauren) like questioning, a focus on symptoms and inter-changeable mental health professionals so that practitioners did not get to know their full story. For Lauren, it was the restricted questioning that was noteworthy

Whereas with like a psychiatrist or the one I went to for that one day or my GP, it was quite like a box tick thing. Like they only ask specific questions about the illness and they didn't ask about anything else (Lauren).

This quote holds a number of valuable points. Reference to ‘box tick’ may imply an experience of being treated like a case, rather than a person. It reminds me of Mark’s experience of being treated like “another day’s work”. In relation to her identity, it seems that a whole part of her is left unseen. Edel furthers this idea by recounting experiences where she *became* her trauma. This occurred where counsellors focused exclusively on

trauma to the neglect of ‘ordinary’ stressors: “it makes me feel that’s all I am”. These ideas relate to the concept of ‘relational identity’ (Ådnøy Eriksen et al., 2014), whereby we construct our sense of self through our relationships with other people.

For Mark and Olivia, it was the focus on diagnosis that obstructed their full personhood from view. Mark described the lack of safety when he meets with new professionals, who do not take the time to get to know him as a person, and instead focus primarily on his diagnosis. “All of a sudden I’ve become a number you know a statistic” (Mark). Similarly, Olivia recalled experiences of being diagnosed, and provided with medication following short meetings with professionals she had never met before: “A lot of GPs are very 'oh yeah yeah whatever we'll just give you this medication and send you on your way'. Dya know they don't actually try to listen to what your issues are or anything or properly diagnose you based on your own personal problems”. Anderson (2012) points to the seductive and risky nature of generalising patterns, narratives and truths about behaviour that can detract from the uniqueness and individuality of each person and their experience.

The distress at being reduced to a category was fuelled by the fear of stigma and lack of transparency within services. Amy and Anna recalled guessing as to the negative and stigmatising judgements that might be made about them. As Amy states, “they could be writing down ‘psycho’”. In dialogic practice, the concept of ‘witness’ positions practitioners as facilitators of conversation, rather than providers of expert knowledge. The aim is to challenge practices of talking ‘about’, whereby people can feel dehumanised and become the object, rather than subject, of meaning (Wilson, 2015). Indeed, dehumanising experiences within mental health services have been documented many times (Bacha et al., 2019; Bracken, 2002; Guilfoyle, 2003; Russo & Sweeney, 2016; Stovell et al., 2016; Tew, 2017)

OD-informed service. For Mark, a contrast was made within the OD informed service, where an unfamiliar professional briefly joined his meetings: “Because Kelly and Patricia know my story from back to front like so ... I feel like I'm actually, or that they're talking about an actual person as opposed to a case”. In the OD service, psychological continuity of his team members means that his team know *him*, not just his difficulties. He begins to say that ‘I feel’ like a person, suggesting an enmeshment of his own identity with that which is seen by professionals. He then corrects himself and clarifies that he is ‘talked about’ as a person. This made me wonder whether about the concept of mentalisation – the ability to distinguish between one’s own and other people’s perspectives (De Meulemeester, Lowyck, Vermote, Verhaest, & Luyten, 2017). Although it was outside the scope of this paper, I found myself wondering about the strength of participants’ sense of identity within the OD informed approach, and whether this strengthens over time in the service.

The words used by participants to describe the service also pointed towards a humanising experience. Lauren experienced her team as a ‘family’. For me, this raised questions about dependency on services, however also indicated that she did not feel a tangible distinction between service user and professionals. It implies the experience of being in a collective group of people, joined by genuine mutual caring. Similarly, Amy describes her team as “like talking to a friend, except a friend who knows a lot”. Here, she acknowledges the expertise of her team, however this does not seem to lead her to feel less equal. Even the treatment meetings were described informally, as a “conversation” (Edel) and “a chat” (Mark).

For Lauren, Amy, and Edel, it was the breadth of conversation that humanised interactions:

It's not robotic. You don't have certain questions you know like with a psychiatrist they say, how are you feeling? What's going on today? Has anything changed? [...] we spoke about school, we spoke about college, we spoke about the future and the voices. (Lauren)

Perhaps the distinction in language between, 'they say', and 'we spoke about' points to the collaborative relationships that are strived toward in OD services.

The breadth of discussion was linked to less restrictive interpretations of their mental health:

Because I can chat about having a bad day. It doesn't have to be all about the past, it doesn't have to be major crisis. If you're going to counselling, it's because there is something majorly wrong in your head. (Amy)

Thus, for Amy, humanisation seems to involve being positioned as an ordinary person with ordinary difficulties. As Edel states, "you could go to Open Dialogue about absolutely anything". In contrast to restrictive illness identities associated with some mental health services (Yanos, Roe, & Lysaker, 2010), there were no such restrictions with the OD approach.

One of the philosophies underpinning dialogic conversations is that of 'orienting toward everyday ordinary life' (Anderson, 2012). Discussions of symptoms and pathology are avoided, as are distinctions between major and minor problems (Olson, Seikkula & Ziedonis, 2014). It may be that this emphasis on stories, not symptoms, contributed to this experience.

Dehumanisation within mental health services has been described as the erosion of personal agency attributed to 'top-down' process of imposing 'expert knowledge' (Wilson, 2015). By contrast, humanising service users acknowledges the validity of their perspectives and identifies them as human beings, capable of understanding and making

sense of their own life. This subtheme is therefore intrinsically linked to the next subtheme, namely *My voice is valued and equal*.

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